

Tuberculosis as a global challenge

A qualitative study of patients' and health workers' perception and management of tuberculosis in Ethiopia and Norway

Mette Sagbakken

Section for International Community health
Department of General Practice and Community
Medicine

Institute of Health and Society

Faculty of Medicine

University of Oslo

Thesis submitted to the University of Oslo
for the degree of Philosophie Doctor (PhD), Oslo 2010

“Tuberculosis, perhaps more than any other disease, is a lens through which society can be viewed (...) Responses reflect how society views those on the margins, from the homeless, drug users, and the HIV infected, to immigrants and felons” (Coker, 2000, p.16).

Abstract

Tuberculosis (TB) is an infectious disease which causes about two million deaths each year. In 1993, the World Health Organization (WHO) declared TB to be a “Global Emergency” due to an increasing number of TB cases and a rise in multi-drug resistant cases in the developed world. Treatment interruption was considered one of the major challenges. WHO introduced the current TB control program DOTS (directly observed treatment, short course) as the tool to control the disease. To prevent further development of resistance against anti-TB drugs it was decided to observe each patient taking their daily dose of medication. The overall aim of this thesis is to explore how patients and health workers perceive and manage TB symptoms and treatment in a high-endemic and a low-endemic setting in the era of DOT(S). The data is based on fieldwork, including in-depth interviews and focus groups with TB patients and health workers, in Addis Ababa, Ethiopia (2001-2002) and in Oslo/Akershus, Norway (2007-2008).

We found that people’s interpretation and management of TB symptoms is influenced by cultural, social and economic factors. TB was, in both contexts, associated with poverty, and subsequently with a disease that affects certain countries or certain segments of a population. TB was viewed as a severe disease in both contexts, but there was variation between individuals to what extent one considered oneself as a likely victim. In the absence of circumstantial causes, such as poverty, patients in a low-endemic setting like Norway, found it difficult to understand why they had developed the disease. There was scarce knowledge about the fact that the disease could be latent. Awareness of early symptoms, such as persistent cough, was low in both contexts. Perceptions of vulnerability, together with the presence or absence of socio-economic barriers or enablers influenced at what time patients would seek help.

The study suggests that health personnel lacked awareness or misinterpreted early symptoms of TB. In Ethiopia, lay categorizations of early TB symptoms converged with diagnostic practices in parts of the professional health sector. The diagnostic process could endure for many months after patients’ first contact with the health services. Similarly, in Norway, we found that patients’ interpretations of early symptoms often were confirmed in the meeting with health personnel. The consequences were prolonged diagnostic processes.

The study shows that patients' ability to manage TB treatment is a product of dynamic processes, in which social and economic costs and other burdens interplay over time. A decision to interrupt treatment can be shaped by past struggles and accrued costs; in which seems financially, socially or emotionally unbearable at the moment of treatment interruption. The burdens related to DOT could also be significant, in patients who did not interrupt treatment. Patients in both Ethiopia and Norway experienced an authoritarian and rigid practice of DOT, which made it difficult to simultaneously attend to demands related to treatment and demands related to other areas of life. The most vulnerable patients, such as those without permanent jobs, suffered from high economic, social and emotional costs.

In conclusion, health personal need more knowledge about typical and atypical symptoms of TB. In low-endemic settings doctors need to be trained to adjust their level of suspicion to the migration history of the patient. In high-endemic settings one should be aware that health personnel may understand and manage TB within a traditional perspective. Patients in both high- and low-endemic contexts need concrete information about the cause of TB, how it is transmitted, how symptoms can be manifested, how the disease can progress and how it can be cured. The study indicates that inequalities that predispose for TB may be reinforced in the patient's interaction with the health services due to a rigid, disempowering practice of DOT. Subsequently, DOT *per se* may add to the chain of structural barriers that patients have to overcome to access and complete treatment. To ensure that TB patients complete treatment one must address the coexisting and interacting crises that follow a TB diagnosis. This would require TB programs to adopt a more holistic approach. Measures that secure early diagnosis may reduce some of the physical, psycho-social and economic costs patients face while undergoing treatment. Measures that empower patients to participate in their own health care may avoid disempowering and humiliating practices.

Sammendrag (abstract in Norwegian)

Tuberkulose (TB) er en infeksjonssykdom som forårsaker rundt to millioner dødsfall hvert år. Verdens helseorganisasjon (WHO) karakteriserte i 1993 økningen i TB som en ”global krise”, da det ble observert en økning i antall TB tilfeller, samt en økning i antall multiresistente tilfeller i industrialiserte land. For å få kontroll over sykdommen introduserte WHO behandlingsprogrammet DOTS (directly observed treatment, short course). Avbrutt behandling ble ansett som en av hovedutfordringene, og for å forebygge videre utvikling av resistens mot anti-tuberkulose medikamenter, ble det bestemt at daglig inntak av medikamenter skulle observeres av helsepersonell. Avhandlingens mål er å utforske hvordan pasienter og helsepersonell oppfatter og håndterer symptomer på TB og påfølgende behandling; i en høy-endemisk og i en lav-endemisk kontekst. Dataene er basert på et feltarbeid, som inkluderte dybdeintervjuer og fokusgrupper med TB pasienter og helsepersonell, i Addis Ababa, Etiopia (2001-2002) og et feltarbeid i Oslo/Akershus, Norge (2007-2008).

Vi fant at fortolkning og håndtering av TB symptomer er påvirket av kulturelle, sosiale og økonomiske faktorer. TB var, i begge kontekster, assosiert med fattigdom og derav med en sykdom som er vanlig i visse land og i visse segmenter av en befolkning. TB ble sett på som en alvorlig sykdom i begge kontekster, men det var variasjon mellom individer i forhold til i hvilken grad de anså seg selv som utsatt for å få sykdommen. I fravær av årsaker betinget av ytre omstendigheter, slik som fattigdom, var det vanskelig for pasienter i en lav-endemisk kontekst som Norge å forstå hvorfor de var rammet av TB. Det var lite kunnskap om at sykdommen kunne ligge latent i kroppen. Det var lav bevissthet rundt tidlige symptomer på TB, slik som vedvarende hoste, i begge kontekster. Forståelse av egen sårbarhet, i kombinasjon med tilstedeværelse eller fravær av sosioøkonomiske barrierer, påvirket på hvilket tidspunkt pasienter søkte helsehjelp.

Vi fant at helsepersonell var lite bevisste eller feiltolket tidlige symptomer på TB. I Etiopia var det samsvar mellom lekfolks fortolkninger av tidlige symptomer og diagnostiske praksiser i deler av den profesjonelle delen av helsesystemet. Den diagnostiske prosessen kunne vedvare i mange måneder etter

pasienters første kontakt med helsevesenet. I Norge ble pasienters fortolkning av symptomer, på liknende måte, ofte bekreftet i møtet med helsepersonell. Konsekvensene av dette var langvarige diagnostiske prosesser.

Vi fant at pasienters mulighet til å håndtere TB behandling var et produkt av dynamiske prosesser, hvor sosiale og økonomiske kostnader og andre byrder virker sammen over tid. En beslutning om å avbryte behandling kan være formet av tidligere strev og oppsamlede kostnader, som økonomisk, sosialt, eller emosjonelt oppleves som u håndterbart på det tidspunktet behandlingen avbrytes. Byrder relatert til behandling kunne også være betydelige blant pasienter som ikke avbrøt behandling. Pasienter i både Etiopia og Norge erfarte en autoritær og rigid praksis av DOT, som gjorde det vanskelig og samtidig å forholde seg til krav relatert til behandling og krav relatert til andre områder i livet. De mest sårbare, som de uten fast arbeid, led under økonomiske, sosiale og emosjonelle kostnader.

Studien peker på behovet for mer kunnskap blant helsepersonell om typiske og atypiske symptomer på TB. I lav-endemiske kontekster er det behov for opplæring av leger slik at de vurderer muligheten for TB ut i fra pasientens migrasjonshistorie. I høy-endemiske kontekster bør man være oppmerksom på at helsepersonell kan forstå og håndtere TB innenfor et tradisjonelt perspektiv. Pasienter i både høy- og lav-endemiske kontekster trenger konkret informasjon om årsaken til TB, hvordan TB smitter, hvordan symptomer manifesteres, hvordan sykdommen kan utvikle seg, og hvordan man kan helbredes.

Studien indikerer at ulikhetene som disponerer for TB kan forsterkes gjennom rigide og krenkende behandlingspraksiser. DOT *per se* kan medføre nye hindringer i rekken av strukturelle barrierer som pasienter møter for å få tilgang til- og for å kunne fullføre behandling. For å sikre at pasienter kan gjennomføre behandlingen må man være oppmerksom på de sameksisterende og samvirkende kriser som følger av at pasienter får en TB diagnose. Dette krever at TB programmer i større grad har en helhetlig tilnærming. Tiltak som kan sikre tidlig diagnose kan redusere noen av de fysiske, psykososiale og økonomiske kostnadene pasienter erfarer under behandling. Tiltak som søker å styrke pasienten slik at de i større grad kan ta ansvar for egen helse, kan forhindre praksiser som skaper avmakt eller er krenkende.

Contents

Abstract	4
Sammendrag (abstract in Norwegian)	6
Contents	8
Preface	11
Acknowledgements	12
List of papers	14
Paper I-IV	14
List of abbreviations	15
1. Introduction	16
1.1 A historical perspective on the management of TB	16
1.1.1 TB - a global emergency	18
1.1.2 Renewed interest in the developed world	19
1.1.3 Management of TB through DOTS	20
1.2 Epidemiology of TB today	22
1.3 The epidemiological situation in the era of DOTS	24
1.3.1 The effectiveness of DOT	25
1.4 Diagnosis and treatment of TB	26
1.5 Challenges in contemporary TB management	28
1.5.1 Challenges related to the concepts used to develop TB control strategies	30
1.6 Case one: Addis Ababa, Ethiopia	35
1.7 Case two: Oslo/Akershus, Norway	36
2. Aims of the study	38
3. Material and Methods	39
3.1 Ethiopia - country profile	39
3.2 Norway - country profile	39

3.3	Theoretical frameworks	40
3.4	Addis Ababa: Participants and study design.....	44
3.4.1	Interviews	47
3.4.2	Focus groups	49
3.4.3	Observations	50
3.5	Oslo/Akershus: Participants and study design.....	50
3.5.1	Interviews	52
3.6	Differences in sample and methods	54
3.7	Interviewer's role, background and perspectives.....	55
3.7.1	Case one: Addis Ababa, Ethiopia.	55
3.7.2	Case two: Oslo/Akershus, Norway.....	58
3.8	Analysis.....	59
3.8.1	Case one: Addis Ababa, Ethiopia.....	59
3.8.2	Case two: Oslo/Akershus, Norway.....	60
3.9	Ethical considerations.....	61
4.	Summary of results	64
5.	Discussion.....	68
5.1	Methodological considerations	68
5.1.1	Reflexivity	68
5.1.2	Trustworthiness and internal validity	71
5.1.3	External validity – transferability	76
5.2	Interpretation and management of symptoms – diagnostic delay.....	78
5.2.1	Addis Ababa, Ethiopia.....	78
5.2.2	Oslo/Akershus, Norway.....	81
5.3	A cross-cultural perspective on diagnostic delay.....	82
5.4	The burden of treatment and its consequences	84
5.4.1	Addis Ababa, Ethiopia.....	84

5.4.2	Oslo/Akershus, Norway	86
5.4.3	Cross cultural perspectives – the burden of DOT	87
5.4.4	Power structures	92
5.5	Ethical questions related to DOT.....	96
5.5.1	Ethical frameworks addressing public health interventions.....	97
5.5.2	How do our findings add to the discussion?.....	99
5.6	Future challenges	103
5.6.1	Ensuring early diagnosis	103
5.6.2	Ensuring treatment and a lasting cure	105
6.	Conclusion.....	109
	References	113
	Appendix A	125
	Appendix B.....	132
	Appendix C.....	136
	Appendix D	137
	Appendix E.....	141
	Errata	143
	Paper I-IV	145

Preface

During my undergraduate studies in social anthropology, I attended a course in medical anthropology, and in one of the classes patients' compliance to medical treatment was discussed in the light of political, economic, social, cultural and individual factors. Tuberculosis was used as an example to highlight some of the research findings and to address the complexity involved in understanding the phenomenon of compliance. I realized the importance of listening to people's own voices, and at the same time being able to contextualize these voices by assessing the structures that frame them. As a masters student I decided to pursue this interest and to focus on compliance with tuberculosis treatment. In October 2001, I left for fieldwork and collected data over a six month period in Addis Ababa, Ethiopia. This fieldwork was the basis of the master thesis I submitted for the degree Master of Philosophy in International Community Health in 2003. As a doctoral student at the Section for International Community Health, Faculty of Medicine, University of Oslo, these data were subject for further analysis and interpretation. This work culminated in the publication of two papers that constitute one part of this dissertation. The second part of this dissertation, and two of the papers, is based on fieldwork from June 2007 to June 2008 among African immigrants in Oslo, and the surrounding county of Akershus, Norway. Throughout this thesis I use the term "we" when I refer to processes where the supervisors have participated. "We" may also be used when describing the part of the study where I used a research assistant. I use the term "I" when I refer to personal reflections and experiences.

Acknowledgements

The research that this thesis reports from has been conducted while I have been affiliated with the Section for International Community health, Department of General Practice and Community Medicine, Institute of Health and Society, Faculty of Medicine, University of Oslo. I have been affiliated with the Section in two periods – as a master student from 2001-2003 – and as a PhD candidate from 2006-2010. The project has been supported financially by EXTRA funds from the Norwegian Foundation for Health and Rehabilitation [grant number 2005/2/0249], by the Norwegian Heart and Lung Patient Organization (LHL), and by Ivar Helles Legat.

From the very beginning of this work, Jan C. Frich and Gunnar A. Bjune have been my supervisors. I want to thank Jan for sharing his broad spectrum of knowledge and for being such a patient, caring and devoted supervisor. In all these years he has encouraged me to continue my work, and unselfishly helped me with practical and academic questions. In his efforts he has always had my best interest in mind. I could not have managed this without him. I also want to thank Gunnar for sharing all his knowledge and insights and for inspiring me to see TB as a disease that connects so many different struggles. I deeply thank him for introducing me to Ethiopia and for facilitating the fieldwork in Addis Ababa. This has been one of the finest journeys of my life. I deeply thank my friend and research assistant Minas Aberra. Because of his ambitions, his strong sense of duty, and his involvement – we managed to conduct a project far beyond my expectations.

The professors and staff at the Section for International Community Health have been a tremendous support and inspiration. I particularly thank the always friendly and problem solving administrative staff, Ragnhild Beyer, Vibeke Christie, and Line Løv. I also thank friends and colleagues that have commented on – and encouraged my work, such as colleagues at the Norwegian Institute of Public Health and colleagues at the Section for Medical Ethics. I want to thank patients and health personnel that participated in this study, and I particularly want to thank patients for sharing their thoughts, struggles and sorrows.

Finally, I wish to thank my family and friends for always being there for me. I thank my sister May for being my role model throughout life. I want to thank her for

protecting me and caring for me in my childhood, and for making me see my potentials in life. I thank Isak and Ulrik, my oldest sons, for supporting me and for being proud and curious about my work. I thank Halvor and Johannes, my youngest sons, for bringing new energy and new meaning into my life. I want to thank my husband Erik for his endless patience and for always meeting me with a smile. Thank you for your involvement and for our valuable nightly discussions. Thank you for your unconditional love and support and for being the person that you are.

Mette Sagbakken – April 2010

List of papers

Paper I-IV

- I. Sagbakken, M., Frich, J.C., Bjune, G.A. (2008). Barriers and enablers in the management of tuberculosis treatment in Addis Ababa, Ethiopia: a qualitative study. *BMC Public Health* 11;8:11
- II. Sagbakken, M., Frich, J.C., Bjune, G.A. (2008). Perception and management of tuberculosis symptoms in Addis Ababa, Ethiopia. *Qual Health Res*, 18, 1356-66.
- III. Sagbakken, M., Bjune, G.A., Frich, J.C. (2010). Experiences of being diagnosed with tuberculosis among immigrants in Norway – Factors associated with diagnostic delay: A qualitative study. *Scand J Public Health*. doi: 10.1177/1403494809357101
- IV. Sagbakken, M., Bjune, G.A., Frich, J.C. Patients' and health professionals' views and experiences with tuberculosis treatment in Norway (submitted manuscript).

I refer to papers by their Roman numerals.

Copyright: Paper I is reprinted in accordance with BioMed Central copyright and license agreement. Paper II and III are reprinted in this thesis in agreement with Sage Publications copyright policy.

List of abbreviations

DALYs	Disability Adjusted Life Years
DOT	Directly observed treatment
DOTS	Directly observed treatment, short course
GP	General practitioner
HBM	Health belief model
IUATLD	International Union against Tuberculosis and Lung Disease
M. tuberculosis	Mycobacterium tuberculosis
NTLCP	National Tuberculosis and Leprosy Control Program
SSB	Statistics Norway
TB	Tuberculosis
WHO	World Health Organization

1. Introduction

Tuberculosis (TB) is an infectious disease which is caused by an acid-fast bacillus, which belongs to the *Mycobacterium tuberculosis* complex. TB transmission begins with a human source, most often a person with cavitory, pulmonary TB. When an infectious patient coughs, sneezes or talks, aerosols are formed in the lungs and expelled. These aerosols contain the micro-particles that carry the bacilli, and can be inhaled by others. The disease affects the lungs in approximately two thirds of cases, but almost all other organs can be the site of TB infection. It is estimated that about one third of the world's population is infected with TB. However, the infection is contained by the immune system in about 90 % of those infected. The TB bacilli can lie dormant for years, being protected by a thick waxy coat. If the immune system is weakened, for example by an HIV infection or treatment with immunosuppressive agents, the chances of developing active TB become much higher (Comstock, 2000, p.139).

TB differs from other diseases with high mortality rates because it has a highly effective treatment available. The greatest burden of TB incidence and mortality is found in the 15-49 age group. Therefore, the economic costs of TB, in terms of lost production, are considerable. Medical treatment usually enables people to return to an active and economically productive life, often with no disability or residual morbidity. By making people non-infectious through medical treatment, transmission can be prevented and the global burden of the disease considerably reduced. TB is ranked as the most cost-effective of all diseases to treat, and is estimated to be the cause of 26 % of all preventable adult deaths (Murray, Styblo, & Rouillon, 1990).

1.1 A historical perspective on the management of TB

In order to understand today's management of TB, we need to see the disease in its historical context. TB has burdened societies since prehistoric times.

Mycobacterium tuberculosis (*M. tuberculosis*), the pathogen causing TB, is suggested to have caused more deaths than any other microbial pathogen. Daniel (2006) has given an account of the history of TB, in which he demonstrates how TB has plagued humankind throughout known history and human prehistory. People suffering from TB have been pictured in early Egyptian art, and *M.*

tuberculosis DNA has been amplified from tissues of both Egyptian and Peruvian mummies. The disease has been described by many varying names, such as the ancient Hebrew word *schachepheth* used in biblical books, *phthisis* used in classical Greek, and *consumption*, *wasting disease* and the *white plague* in modern English. TB has surged in major epidemics and then subsided, similar to other infectious diseases. However, the time scale of TB challenges common explanations for epidemic cycles (Daniel, 2006). TB reached epidemic proportions in Europe and North America during the 18th and the early 19th centuries. At that time death rates in cities like London, Stockholm, and Hamburg approached 800-1000 per 100 000 population per year (Daniel, 2006). A likely explanation for these figures is that TB transmission increased due to increased population density and crowded living conditions, while other risk factors, such as poor nutrition, increased the risk of progressing from latent to active disease (Lönnroth, Jaramillo, Williams, Dye, & Raviglione, 2009). In the face of an enormous TB prevalence, parts of society responded by romanticizing the disease. Writers and artists described the pallid faces and skinny bodies of the TB diseased as attractive, interesting and sensitive in expression (Daniel, 2006). One of the famous quotes is Charles Dickens' (1812-70) description of the death of Smike in *Nicholas Nickleby*; "[As] the mortal part wastes and withers away, so the spirit grows light and sanguine" (Dickens, 1986, p.739). However, TB first of all caused fear, not only of catching the disease, but also a fear that one would "catch" or be associated with the predisposing factors linked with TB; such as poverty, poor nutrition, alcoholism, and drug-dependency (Coker, 2000, p.6).

During the first meeting of specialists in internal medicine, held in Paris in 1867, TB was found to be the most frequent disease that specialists dealt with. Subsequently, a series of scientific meetings and international congresses devoted particularly to TB were initiated. This eventually led to the establishment of the International Union against Tuberculosis and Lung Disease (IUATLD) in 1920 (Enarson, 2000, p.55). Towards the end of the 19th century, after death rates from TB had started to decline, two historic events occurred that had a tremendous impact on the diagnosis and treatment of the disease: The discovery of the tubercle bacillus in 1882, by Robert Koch (1843-1910), and the discovery of X-rays by Wilhelm Konrad Röntgen (1845-1923) in 1895. These two events led to a wave of

research that eventually resulted in the development of the BCG vaccine in the 1920s, as well as effective medical treatment. Some of the major breakthroughs were the discovery of the anti-tuberculosis drugs streptomycin in 1944, isoniazid in 1952, and rifampicin in 1965 (Daniel, 2006).

1.1.1 TB - a global emergency

Half a century after the introduction of effective therapy and 111 years after *M. tuberculosis* was identified, the World Health Organization (WHO) declared that TB represented a “Global Emergency”. Dr. Kochi, manager of the WHO Tuberculosis Programme, emphasized, in a speech in 1993, that TB was humanity’s greatest killer, and that the disease was out of control in many parts of the world. In light of all the scientific breakthroughs how was such a development possible? From the early and mid-19th century, at the same time as knowledge of TB advanced, the prevalence and mortality rates had started to decline in Europe and North America. Improved social and living conditions, better nutrition, and introduction of sanatoria, have been put forward as explanations for the decline. Herd immunity, due to natural selection of a genetically more resistant population, has also been suggested to have played a role (Daniel, 2006; Lönnroth et al., 2009). TB was no longer considered a threat to the developed countries, and funding and interest for TB control and TB related research became greatly reduced. Loss of funding and interest in TB control caused a loss of awareness, a loss of clinical competence, as well as a dismantling of infrastructure related to TB control management (Ogden, Walt, & Lush, 2003). The discovery of the BCG vaccine and the development of effective therapeutic regimens would most probably have had a much greater impact on TB control if adequate resources had been available in the developing world. The opportunities given through the medical advancements were first of all implemented in the developed world. Attempts to transfer good results from industrialized countries, by using the same methods, were successful in only a few other countries. In the poorest countries, where the majority of the cases lived, infrastructure for providing services could be absent. Populations were scattered, and communication needed for surveillance and ensuring accessibility to the existing health-services was insufficient. In addition, economic resources were far from sufficient to deal with the disease burden (Enarson, 2000, p.60-61).

There were other contributing problems to TB control in the developing part of the world. One of the earliest interventions in low-income countries, during the 1960's, was the use of isoniazid alone in the treatment of TB. It was cheap, showed good results, was easy to apply, and received support from the executive director of the IUATLD and from the Director General in the WHO. This strategy led to the proliferation of isoniazid resistance and formed the basis for the present problem of multi-drug resistance (Enarson, 2000, p.61). Another strategy was based on the importance of active case findings. The idea was that if one obtained a modest level of treatment-success in a large number of cases it would be a more effective way of reducing the disease burden than if a high level of treatment-success was obtained in a restricted number of cases. After recommendations from the WHO, most governments in low-income countries developed national TB control programs. After a few years with the recommended strategy, millions of TB cases were reported to the WHO. Regular surveys from countries in East Asia showed that more than half of the sources of transmission of TB were cases being treated, but not cured. In addition, the majority of these cases had developed resistant strains. The strategy had failed, and the ineffective treatment made the epidemiological situation far worse than if the patients had been left untreated (Enarson, 2000, p.61-62).

1.1.2 Renewed interest in the developed world

While attention to and funding for TB had vanished, the disease returned in the developed world. Reichman (1991) describes this as the “U-shaped curve of concern” by showing how changes in TB incidence are related to resource distribution. The interest and concern over TB increased in the mid-1980's as a result of an increasing number of TB cases, as well as an alarming rise in multidrug resistant cases, in the developed world. Although drug resistant strains had long been diagnosed in high-endemic contexts, multidrug resistance was a new problem in the developed world. The main key to the renewed interest are linked to the HIV-related outbreaks of TB in New York City in the late 1980's and early 1990's. The spread of the disease from the poor and the marginalised to middle class Americans caused a resurgent fear of TB. The city authorities in New York initiated a large campaign to combat the epidemic, including the implementation of directly observed therapy (DOT) and incentives such as travel

token reimbursement, free lunches, and food coupons to encourage compliance. The use of detention, based on previous failures of completing treatment, also became a part of the strategy. The efforts showed that with sufficient attention and resources including individualized treatment plans, treatment offered in a variety of settings, food-support, and close follow-up; TB to a large extent could be controlled. However, the use of detention, based on judgment of previous behaviour, and not on assessment of whether the person actually posed a significant risk to others due to this behaviour, caused a debate about the grounds of coercive measures (Coker, 2000, p.47-119; Ogden et al., 2003).

1.1.3 Management of TB through DOTS

In 1991, delegates to the WHO's 1991 World Health Assembly set two targets for national TB control programs; to detect at least 70 % of all new sputum smear-positive cases arising each year and to cure at least 85 % of them (Dye, Hosseini, & Watt, 2007). During the early 1990's essential methods for TB diagnosis and treatment were integrated into the WHO's TB control strategy; DOTS, became the main tool to reach these targets. Treatment interruption was considered one of the major challenges in TB control. To prevent further development of resistance against anti-TB drugs (rifampacin in particular), it was decided to emphasize the control of each patient taking their daily dose of medication. Subsequently, the WHO developed an extensive strategy that centered on directly observed therapy (Lienhardt & Ogden, 2004). DOTS, is still the internationally recommended strategy for TB control and is comprised of five components which emphasize:

1. Sustained financial and political commitment,
2. Case detection through passive case finding using quality ensured sputum-smear microscopy,
3. Standardized short-course anti-TB treatment given under direct observation,
4. Securing of a regular, uninterrupted supply of high quality anti-TB drugs, and
5. Standardizing recording and reporting (The World Health Organization [WHO], 2009a).

The introduction of DOTS led to a debate between representatives from the scientific community and policymakers who were eager to implement the global

strategy. The DOTS strategy was criticized for not including a focus on research and development of new vaccines and new drugs, and there was a worry that the implementation of DOTS would imply even less money being allocated to such research. Many saw DOTS as an oversimplified measure based on conventional methods, and expressed concerns about the effectiveness of such an approach (Ogden et al., 2003). Another source of debate was that directly observed treatment, one of the components of DOTS, was controversial from an operational as well as from an ethical and human rights perspective (Porter & Ogden, 1997; Hurtig, Porter, & Ogden, 1999). A strict and universal application of DOT was developed on the basis of a few controlled studies, and transferred to a variety of other social, economic and cultural contexts without clear guidelines for implementation (Lienhardt & Ogden, 2004). It has been claimed that there has been too little focus on whether the implementation in different settings is user-friendly, to what degree clinics and health personnel are culturally-sensitive enough, and whether or not the coercive elements (enforced daily clinic-based treatment) are justifiable ethically (Porter & Ogden, 1999; Lienhardt & Ogden, 2004). These arguments and concerns led to a randomized controlled trial of DOT versus self-supervision of treatment in South Africa, which concluded that the use of DOT showed no benefit in terms of cure-rates (Zwarenstein, Schoeman, Vundule, Lombard, & Tatley, 1998). The study results were not taken into consideration by the WHO due to problems in the study design. Another two randomized controlled trials followed. One of them, conducted in Thailand, showed a clear benefit from DOT versus self-administration. In this setting DOT was being conducted by a family member and with weekly support visits from health personnel (Kamolratanakul et al., 1999). The other trial was conducted in Pakistan and showed no difference between DOT and self-administration. However, higher cure rates were seen in the group where DOT was provided by a family member compared to a health worker (Walley, Khan, Newell, & Khan, 2001). The lessons from these three trials were inconclusive, but raised serious doubts about the effectiveness of TB control programs when DOT executed by health personnel where key elements (Lienhardt & Ogden, 2004).

1.2 Epidemiology of TB today

Today, TB is still a major global public health concern. In 2008, there were an estimated 8.9–9.9 million incident cases of TB, 9.6–13.3 million prevalent cases of TB, 1.1–1.7 million deaths from TB among HIV-negative people and an additional 0.45–0.62 million TB deaths among HIV-positive people (best estimates of 9.4 million, 11.1 million, 1.3 million and 0.52 million, respectively) (WHO, 2009b). The incidence of TB has gradually increased over the last 20 years, from about 6.6 million cases in 1990, to 8.3 million cases in 2000, and 9.2 million cases in 2006. Most of the estimated cases in 2007 were in Asia (55 %) and Africa (31 %), and only a small proportion of TB cases are found in the Eastern Mediterranean Region (6 %), the European Region (5 %) and the Region of the Americas (3 %) (WHO, 2009c). There has been a disproportionate burden of HIV and TB infection, disease, and death in the African region. In 2003, there were an estimated 8.8 million new cases and 1.7 million deaths from TB. Even though only 11 % of the world's population lives in Africa, 27 % of cases and 31 % of deaths occurred in this region. Of the 9.4 million new TB cases in 2008 an estimated 1.2–1.6 million (13–16 %) were HIV positive (best estimate of 1.4 million). 78 % of the HIV-positive cases were in the African region (WHO, 2009b, p.5; Corbett, Marston, Churchyard, & De Cock, 2006).

In the developed world, prevalence and mortality rates have steadily declined among the general population from the early 19th century. However, TB is becoming more prevalent among certain minority groups, as well as among the homeless, people with alcohol dependence, and people with drug addiction. Lönnroth et al. underlines that “the TB burden follows a strong socio-economic gradient between countries, within countries and within communities, and the poorest have the highest risk” (Lönnroth, Jaramillo, Williams, Dye, & Raviglione, 2009, p.2243). Studies that have assessed the impact of TB in vulnerable populations show that there is a strong association between social suffering and TB (Lönnroth et al., 2009). In England and Wales notifications of TB increased by 12 % from 1988 to 1992. There was an increase of 35 % among the poorest 10th of the population, a 13 % increase in the next two 10ths, and no increase among the more affluent (70 %) part of the population (Bhatti, Law, Morris, Halliday, & Moore-Gillon, 1995). In the USA, the epidemics of TB in the 1980s and the 1990s mostly affected the socio-economically underprivileged. In the mid-1980's, active

TB rates among the homeless in New York were estimated to be 968 per 100 000 population, compared to 23 per 100 000 for the whole population of New York (Coker, 2000, p.51). It has been argued that a more market oriented approach to public health has changed both the rationale and distribution of health services and created an 'ecological niche' in certain areas, such as inner American cities, within which infectious diseases like TB can spread more easily (Wallace & Wallace, 1999). Within developing countries there are large differences in the prevalence of TB. In the slums of Delhi and Calcutta the prevalence is found to be 50 per 1000 compared with 3 per 1000 for non-slum areas (Ogden et al., 1999). Even if we observe an increase of TB among some groups in industrialized countries, the burden of TB is mainly carried by the developing countries, where 95 % of all TB cases occur (Lienhardt & Ogden, 2004). The TB afflicted has had few health advocates and the funding of TB control continues to be very low compared to infectious diseases like AIDS and Malaria (Gandy & Zumla, 2002).

In a low-endemic, high-income setting such as Norway, with a total population of 4.7 million people, 307 new cases of TB were reported in 2007 (Winje, Mannsåker, Heldal, & Dahle, 2008). Foreign-born persons accounted for 243 (79 %) of these cases. Among Norwegian-born individuals with TB (including second generation immigrants), the median age at the time of diagnosis was 74 years. The incidence of TB in Norway is highest among people who originate from Africa and Asia, and the rates reflect the epidemiological situation in the countries of origin. In 2005, the number of reported TB cases were highest among people with the following countries of origin; Somalia, Ethiopia, Vietnam and the Philippines (listed in order of number of cases) (Winje, Mannsåker, Heldal, Brantsæter, & Dahle, 2006b). In 2006, the number of reported TB cases were highest among people with the following countries of origin; Somalia, Ethiopia, Pakistan, Thailand, and the Philippines (listed in order of number of cases) (Winje, Mannsåker, Heldal, & Dahle, 2007).

In a high-endemic, low-income setting such as Ethiopia, with a total population of approximately 77.1 million people (Population Reference Bureau, 2007), 314,267 new TB cases were reported in 2007 and there was an estimated incidence rate of 378 cases per 100,000 population. The TB case detection rate is very low compared to the WHO's target of detecting 70 % of infectious TB cases; with only a 28 % detection rate

of new smear positive cases, and a 40 % detection rate of all cases (WHO, 2009d). Ethiopia ranks seventh among the world's 22 high-burden countries (WHO, 2009b, p.5).

1.3 *The epidemiological situation in the era of DOTS*

In 2000, 148 countries, including all 22 high burden countries, which bear 80 % of the estimated cases, had adopted a version of DOTS. However, many countries have continued to show slow progress in controlling TB. There has been a slow expansion of control efforts and progress in case detection has remained slow. In a number of sub-Saharan countries case rates have risen dramatically, mainly because of the AIDS epidemic (Raviglione, 2003). In 2005-2006, the new “Stop TB strategy” was developed by the WHO in response to challenges not adequately addressed in the initial DOTS strategy. The “Stop TB strategy” was built on the DOTS strategy, but sought to address sustainment, improvement and acceleration of quality DOTS expansion. The new strategy is also concerned with new challenges related to multi-drug resistant TB, the intersecting epidemics of TB and HIV, lack of involvement of private practitioners, challenges related to weak health systems, further involvement and empowerment of patients and their communities, and enabling and promoting research (WHO, 2009c).

It has been documented that treatment according to the principles of DOTS is a cost effective public health intervention when evaluated with regards to disability adjusted life years saved (DALYs) (the sum of years of potential life lost due to premature mortality and the years of productive life lost due to disability) (Lönnroth et al., 2009). Further, cost benefit calculations have shown that curative TB control is a good investment in society (Lönnroth et al., 2009). The number of notified cases of TB in 2008 world wide was 5.7 million, equivalent to 55–67 % of all incident cases (best estimate of 61 %). This is 10 % less than the Global Plan milestone of a case detection rate of 71 % in 2008. Among patients in the 2007 cohort, 86 % were successfully treated. This is the first time the target of 85 % has been exceeded at a global level since it was set in 1991 (WHO, 2009b). However, studies investigating DOTS' effect on TB incidence, treatment completion, and cure do not provide a solid assurance of the value of DOTS as the main strategy in TB control. The implementation of DOTS has been associated with a decline in TB prevalence and incidence in Peru, Cuba, China, parts of India and the USA. Still, in areas where there has been a significant decline it has been difficult to separate the effect of DOTS and the effect of general socio-economic

development (Lönnroth et al., 2009). Dye, Lönnroth, Jaramillo, Williams, & Raviglione (2009), investigated trends in TB incidence and their determinants in 134 countries. They found that the incidence rate declined more quickly in countries that had a higher human development index, greater health expenditure, lower child mortality, and improved sanitation. Further, incidence rates declined more quickly in high-income countries with lower immigration and in countries with lower HIV infection rates. General development measures were found to be the dominant explanatory variables within regions as well. A possible causal link between TB incidence and control efforts were found only in Latin America and the Caribbean, in which lead to the conclusion that TB control program's effect on TB transmission and incidence rates is highly insecure (Dye et al., 2009). A systematic review assessing long term efficacy of standard short course regimens (6 months) found that there was a wide variation in TB recurrence (ranging from 0 % to 14 %) after completion of treatment. The authors conclude that despite standard DOTS regimens being implemented for more than a decade, few studies have assessed the ability of such regimens to result in a lasting cure (Cox, Morrow, & Deutschman, 2008).

1.3.1 The effectiveness of DOT

Even though the TB control programs' effect on transmission and incidence rates may be insecure, there is little doubt that the different components of the DOTS strategy have revitalized and strengthened TB control efforts. However, the way in which the DOT component of DOTS contributes to the treatment and cure of TB is a relationship that has yet to be rigorously evaluated (Verma, Upshur, Rea, & Benatar, 2004). Due to the impact of DOT on patient autonomy, this is the component of the treatment strategy that has remained controversial. Volmink and Garner (2007), set out to compare DOT with self-administration of treatment or different DOT options. They conducted a systematic review of 11 randomized and quasi-randomized controlled trials that compared DOT conducted by a health worker, family member, or community volunteer with self administration of treatment at home. They found that there was no significant difference between DOT and self-administration in terms of cure (assessed in four trials). DOT provided at home compared to DOT provided at a clinic indicated a small advantage with home based DOT in terms of cure (assessed in three trials). No significant difference in clinical outcomes was found between DOT given at a

clinic compared to DOT given by a family member or community health worker (assessed in two trials), or for DOT given by a family member compared with a community health worker (assessed in one trial). Further, in two trials comparing DOT and self-administration of medication among intravenous drug users (TB prophylaxis), no statistically significant difference was found between DOT and self-administration. The authors conclude that results from low-, middle-, and high-income countries provide no evidence that DOT, compared with self-administration of TB treatment, has any quantitatively important impact on cure or treatment completion (Volmink & Garner, 2007). DOT has also been recommended to improve adherence for patients with HIV infection being treated with antiretroviral treatment. A systematic review and meta-analysis of randomized trials of DOT versus self-administered antiretroviral treatment showed that DOT offered no benefit compared to self-administered treatment. The authors suggest that the reason why both this review and Volmink and Garner's review provide no evidence that supports the use of DOT, could be linked with the burden associated with frequent clinic visitations, resistance caused by infringement of patients' autonomy, a desire among patients to be in control of their own treatment, absence of the intervention, or patients adhering to the treatment independent of any intervention (Ford, Nachega, Engel, & Mills, 2009).

1.4 *Diagnosis and treatment of TB*

Bacteriological diagnosis of TB still relies on detection of acid fast bacilli on microscopic examination and on culture; routine diagnostic methods that are very similar to those used 100 years ago. Diagnosing drug resistant TB (TB that is resistant to any first line anti-tuberculosis drug) is more demanding because it needs growth on culture and the incorporation of anti-tuberculosis drugs takes six to eight weeks and requires special laboratory facilities. These are largely unavailable in high-endemic, low-income settings (Grant, Gothard, & Thwaites, 2008). In patients with extra-pulmonary TB, and in patients with TB/HIV co-morbidity, the sputum smear is often negative. Since low-income settings have limited access to mycobacterial culture (and PCR-based nucleic-acid amplification tests), the most common way of diagnosing such cases in low-income setting are therefore through clinical diagnosis, supported by radiology . In 2006, the WHO issued guidelines for the diagnosis of smear-negative and extra-pulmonary TB. These were aimed at settings with high prevalence of HIV infection.

Case definitions for smear-negative TB have also been developed. However, studies from Africa show that the results vary (Maartens & Wilkinson, 2007).

Conventional short-course treatment for TB has been the same for decades. The most common treatment combination is isoniazid, rifampicin, pyrazinamide, and ethambutol for 2 months, followed by isoniazid and rifampicin for 4 months. This treatment regimen is highly effective on patients with TB, including those who are HIV positive, and is a part of the current DOTS strategy (Maartens & Wilkinson, 2007).

Side-effects are common, and hepatotoxicity to isoniazid is considered a serious problem. Other side-effects include dermatological reactions (e.g. flushing), gastrointestinal intolerance (e.g. nausea, vomiting, diarrhea) hypersensitivity (e.g. rash, fever), neurological effects (e.g. peripheral neuropathy), hematological effects (e.g. thrombocytopenia, hemolytic anemia), as well as different renal diseases. Such side-effects can lead to drug discontinuation or more serious morbidity or mortality (Forget & Menzies, 2006).

An extended variant of the DOTS strategy, DOTS plus, is used in cases with drug resistant TB (Maartens & Wilkinson, 2007). To be able to detect drug resistant TB, this part of the program recommends an additional investment in facilities for culture and drug susceptibility testing. Management of drug resistant TB is difficult because there is a lack of randomized controlled trials providing evidence related to treatment. Furthermore, second line drugs are expensive and weak, they can give severe side-effects, and many patients have an advanced disease that requires extensive treatment. Treatment of multidrug resistant TB can also be complicated by HIV co-infection and interrupted provision of second line drugs (Grant et al., 2008).

Preventive therapy is found to reduce TB incidence in both HIV-positive and HIV-negative patients. Such therapy is considered a successful component of TB control in Europe and North-America. Problems in identifying those at risk, uncertainties related to the effects in high-endemic settings, and insecurity about cost-effectiveness and acquired drug resistance has restricted the implementation in high-endemic, low-income settings (Maartens & Wilkinson, 2007).

1.5 Challenges in contemporary TB management

Delay in seeking treatment/delay in receiving a diagnose (patient and health care system delay) and interruption of treatment are two fields that both in the pre-DOTS era and in present time are considered as main barriers for the successful control of TB. Diagnostic delay leads to an increased period of infectiousness in the community and exacerbates the disease in affected individuals (Lienhardt, 2001). Non-adherence to treatment may result in prolonged infectiousness, drug resistance, relapse, and death. Treatment interruption thus poses a serious risk both for the individual and the community (Volmink & Garner, 2007). Diagnostic delay and treatment interruption have been described as “twin problems” due to their complex, similar and interrelated causes (Rubel & Garro, 1992). Furthermore, in the context of physical, geographic, economic, and socio-psychological barriers to treatment, early diagnosis may serve as an important precondition for managing a long treatment regimen (Lienhardt, 2001). Some studies suggest that diagnostic delay is related to how patients perceive and manage early symptoms (Demissie, Lindtjorn, & Berhane, 2002; Liefhoghe, Baliddawa, Kipruto, Vermeire, & De Munynck, 1997; Watkins & Plant, 2004). Others studies have emphasized stigma and economic costs related to obtaining the diagnosis (Rubel & Garo, 1992; Sanou, Dembele, Theobald, & Macq, 2004; Johansson & Winkvist, 2002). A recent review of quantitative studies identified several factors associated with diagnostic delay, such as; HIV infection; coexisting chronic cough or lung diseases; negative sputum smear; extra-pulmonary TB; rural residence; poverty; poor access to care (geographic or socio-psychological barriers); initial visitation of a government low-level healthcare facility, private practitioner, or traditional healer; old age; female sex; low awareness of TB; incomprehensive knowledge; history of immigration; low education level; alcoholism and substance abuse, and stigma (Storla, Yimer, & Bjune, 2008). Other health related factors that lead to an increased risk of delay were generally poor health, smoking, less severe/indifferent symptoms, and an absence of hemoptysis. Most of the studies, independent of high or low endemic context, reported a total diagnostic delay within the range of 60-90 days (Storla et al., 2008). A factor that gave an increased risk of delay in one study could give a decreased risk in another study. This indicates the need to explore context specific factors. Most factors were found to influence *both* patient and health care delay, but factors such as poverty, low access to health care facilities, and incomprehensive knowledge of TB were more linked to patient

delay. Factors such as coexistence of chronic cough and/or other diseases, having extra-pulmonary or negative sputum smear TB, less severe and indifferent symptoms, absence of hemoptysis, and use of traditional or private practitioners first, were more linked to health care system delay. Generally, many studies describe difficulties that patients have in reaching the local treatment unit of the national TB program due to poverty, distance and/or stigma associated with these clinics. Another factor of vital importance is repeated consultations by a patient at the same level in the health care system, without receiving a diagnosis (Storla et al., 2008). Such treatment patterns will evidently increase poverty related problems in accessing and adhering to relevant treatment.

Studies from both low- and high-income countries have shown that between 20-50 % of patients with TB do not complete their treatment regimes (Sackett & Snow, 1979, p.14; Addington, 1979; Cuneo & Snider, 1989). In recent years, there have been a large number of qualitative studies conducted on TB and adherence in the developing world. In a systematic review of 44 qualitative studies on patient adherence to TB treatment, eight major themes were identified: barriers related to how treatment and care were organized; patients' interpretation of illness and wellness; financial burdens related to treatment; knowledge, attitudes and beliefs related to treatment; law and immigration; personal characteristics; side-effects; and family and community support. The review concludes that a more patient-centered approach and more attention to structural barriers are needed to improve treatment adherence (Munro et al., 2007a). The intertwined problems of delay in seeking treatment and interruption of treatment are clearly demonstrated by the main findings in the literature: People's understanding of symptoms and treatment may affect health seeking behavior throughout the course of the disease from acting on the first symptoms, until treatment completion. Indirect or direct costs related to diagnostic procedures, loss of time, or transportation to relevant health services also represent major barriers. Similarly, the social stigma that is attached to TB seems to represent a barrier in all stages of the disease.

However, the literature illustrates that treatment adherence is a complex, dynamic phenomenon. To understand such a phenomenon studies exploring a wide range of preceding, interacting, and contextual factors need to be conducted. Given the importance of long-term medication adherence in relation to TB, more studies are needed to better understand people's experiences with TB and the long treatment regimen (Munro, Lewin, Swart, & Volmink, 2007b). There is a particular lack of

research exploring lay understandings of TB and its treatment and how these influence how people act upon symptoms and continue or discontinue treatment at particular times (Munro et al., 2007a; Munro et al., 2007b). Few studies have, for example, used qualitative methods to explore patients' perception and management of TB during different phases of the disease and its treatment. Patients may change their perception and behavior from the onset of symptoms to completion of treatment. Exploring the rationale behind such changes may bring us closer to an understanding which would in turn facilitate an improved management of patients with TB. However, Munro et al. (2007a) emphasize that any further research on patients' experiences in relation to TB and adherence needs to include and explore the social, economic, and geographic contexts in which the patient is embedded.

DOTS have been implemented globally, including most countries in Europe (WHO, 2005). However, few studies have investigated TB patients' management of symptoms and treatment in a low-endemic context. Further, few studies have explored patients' and health workers' experiences with DOT in low-endemic, high-income parts of the world. We therefore know little about whether patients face barriers similar to those described from low-income, high-endemic settings.

1.5.1 Challenges related to the concepts used to develop TB control strategies

A vast number of studies exploring reasons for diagnostic delay and patient non-compliance have been conducted, both before and after the implementation of DOTS. Even though more recent studies and reviews seem to address structural barriers to a further extent, there has been a general trend of focusing more on the behavioral aspects among patients, and less on the structural barriers that may prevent patients from obtaining a diagnosis and complete treatment (Farmer, 1999). When focusing on behavioral aspects, there has been a tendency to "blame" the patient and in particular the term "non-compliance" has been used in a paternalistic manner. Haynes (1979, p.3), demonstrates that "non-compliance" is linked with blame and sin since the first recorded incidence of human non-compliance within the Judeo-Christian tradition was Eve eating the fruit of the tree of knowledge in the Garden of Eden. Even though Eve was persuaded by a snake, and as such her "health belief model" was changed, she, and not the snake, had to carry the blame. Haynes (1979, p.1-2), summarizes the common use and

interpretation of the concept by defining compliance as: “the extent to which a person’s behavior coincides with medical or health advice”. Such an interpretation incorporates the biomedical perspective in which patients are expected to be passive recipients of health personnel’s instructions (Munro et al., 2007b).

Donovan and Blake turn to the dictionary definition where; “to obey, submit, defer or accede to instructions” are the corresponding synonyms (Donovan and Blake 1992, p.507). Such definitions imply that all patients *should* comply with the instructions provided by health personnel, and subsequently that non-compliance is to be considered as deviant behavior.

Trostle (1988) has reviewed historical material about the twentieth century and found that what clinicians nowadays refer to as “compliance”, used to be presented as a matter of physician “control”. Trostle argues that medical compliance is better understood if viewed as an ideology; “a system of shared beliefs that legitimize particular behavioral norms and values at the same time that they claim and appear to be based on empirical truths” (Trostle, 1988, p.1300). According to Trostle, such ideologies facilitate transformation of power into authority and legitimate control. Trostle points to the inconsistent results derived from research on patient compliance, and relates it to how the ideology of the concept compliance has transformed theories physicians have on proper patient behavior into certain research questions. This in turn has produced certain research results. Such research questions have ignored health related behavior that contradicts the physicians’ view, and has resulted in potentially coercive medical interventions that appear to be right (Trostle, 1988). By using certain scientific concepts, specific agendas can be concealed. Further, by using certain concepts, those in control can narrow or adjust their targets in accordance with their definition of the word.

In line with an extensive focus on patients’ behavior, socio-demographic variables such as age, ethnicity, race, income and education have been thoroughly explored in studies on compliance with TB treatment. Sumartojo (1993) concludes that these factors are inconsistent or unreliable predictors of patient adherence, and argues that focusing on such characteristics may lead to a bias among the providers judging people with certain characteristics to be potential defaulters and thus limiting the expectations of compliance.

Homedes and Ugalde (1993) reviewed 37 empirical studies on compliance with medical treatment in developing countries. They found that most research done on

compliance in developing countries is carried out from a bio-medical perspective. Information on what type of rationality was involved in patients' decision-making was limited. This made it difficult to understand the motives behind health seeking behavior and to address appropriate action towards higher patient compliance. Social scientists have, and still, argue that the language of "compliance" has failed to recognize patients' active participation in their own health care, and that many of the reasoned decisions for being "non-compliant" may have been ignored due to such a perspective. Donovan and Blake (1992) argue that research shows that patients actively make choices about their health within the context of enablers and barriers in their lives, and so "non-compliance may thus not be deviance, but reasoned decision-making" (Donovan and Blake, 1992, p. 508). Some have suggested that the concept of "adherence" should replace "compliance" because it includes patients' agency in a better way (Sumartojo, 1993). Adherence refers to consistency in people's own ideas and beliefs, and includes a perspective where a patient faithfully follows a particular set of beliefs related to how they interpret and manage their own disease (Sumartojo, 1993). However, to fully understand the concept of treatment adherence one needs to understand that different medical systems co-exist in different societies and that these different medical systems can be used at the same time by the same individual. Use of different medical systems can be related to different stages of a disease or be a result of separate approaches towards the treatment of symptoms and the treatment of cause. The variety of practices may imply adherence to one or several belief systems, or it can indicate lack of adherence to any particular system (Stoner, 1986; Helman, 1978).

The concept of "concordance" has also been suggested as a means to understand and address patient compliance from a different perspective. Concordance emphasizes the importance of health personnel being able to acknowledge and take into account patients' decision making capabilities, and with patients being more active in stating their needs and constraints. Central to the use of this concept is the sharing of information and knowledge between the recipient and the provider of health services (Mullen, 1997). DOT has been criticized for moving away from promoted adherence- and concordance models of communication to the more traditional medical approach in which patients remain passive recipients of treatment. A consequence of this is that patients may feel forced or pushed to follow medical rules or advice, and might not adhere to the proposed treatment even if they do "comply" at certain or all stages. Some

of the supporters of DOT have argued that the effect of an intervention, such as DOT, is meant to go beyond the observation of medication intake, and that the use of the concept concordance would be a step in the right direction. By emphasizing an agreement between the patient and the health care workers, about whether, when, and how medicines are to be taken, one will, to a greater extent, promote the protection of civil rights and patient autonomy (Maher, Uplekar, Blanc, & Raviglione, 2003).

Another important and complicating issue in the debate about diagnostic delay and treatment compliance as the main barriers in TB control is that both health conditions and the delivery of health-care vary in developing countries. In these countries, where a large part of the population have only recently been given access to modern medical care, availability, accessibility, costs for patients, and the quality of care are all factors that may be barriers. These barriers may make it impossible to render or make it impractical to access and adhere to medical regimens, even in places where the knowledge of TB is good and the patients are highly motivated to seek care within the formal biomedical system. Some of these issues are also highly relevant in western societies. An important early study (Curry, 1968) in San Francisco, California, demonstrates this. Health workers attributed barriers to continuation of TB treatment to social and cultural characteristics of the patients such as lack of education, ignorance, old age, alcoholism and language problems. Patients on the other hand ascribed treatment irregularity and dropouts to problems with the organization of care and the interaction with the health workers. Among the barriers described by the patients were rigid, repeating and time-consuming routines, lack of continuity among the physicians, not treating families as a unit, lack of adequate explanations related to the diagnosis and treatment of TB, punitive staff practices, prolonged waiting in overcrowded rooms, and inconvenient times and place for appointments. When clinical staff became aware of these viewpoints the treatment services were re-organized and missed appointment rates fell from 26 % to 4 % in 6 years (Curry, 1968).

Paul Farmer (1997), a physician and anthropologist, has argued that compliance is a problematic concept because it assumes that all patients are equally able to comply with anti-tuberculosis therapy. He argues that the focus on patients' agency is exaggerated, particularly in the biomedical literature. According to Farmer, it is social

scientists that have insisted on the causal role of culture or personal traits when explaining treatment interruptions. Farmer argues that such studies have failed to recognize the wider influences on patients' lives such as poverty, conflicts, political instability, racial and gender inequalities. Treatment of TB patients needs measures that recognize how wider structural forces limit patients' ability to access, maintain and complete therapy. This point is underlined in Farmer's well-known quote: "Throughout the world, those least likely to comply are those least able to comply..." (Farmer, 1997, p. 353). Farmer emphasizes that a large proportion of the patients with TB world-wide go undetected because of a lack of access to medical facilities, or having difficulties in making regular clinic appointments. Studies suggest that many of the therapy interruptions are due to failures or poor treatment imposed by health care workers or the health care system. Health workers may not comply with proper prescribing practices (e.g. provide suboptimal dosage, mono-therapy). Patients may be exposed to arrogant, humiliating or patronizing behavior. Poor communication or poor follow-up can lead to misunderstandings and subsequent interruptions. Treatment interruptions are often caused by an interrupted supply of drugs, or by demands set by the system causing social, practical and economic costs impossible to manage by patients. Thus, the issue of "compliance", and the growth of multi-drug resistant TB, cannot be reduced to a discussion of different categories of patients and their degree of co-operation with health workers (Farmer, 1997; Gandy & Zumla, 2002).

In 2005, 187 countries had implemented DOTS (WHO, 2005). A global application of DOT, to ensure patient compliance with treatment, has been promoted and transferred to a variety of other social, economic and cultural contexts. How do people living with TB in different parts of the world perceive and manage their symptoms and treatment in the era of DOT? Are there particular barriers or enablers associated with disparity in accessible resources? Are patients being treated by DOT in low-endemic settings experiencing barriers similar to those experienced in high-endemic settings? How do health personnel from different parts of the world interpret and manage TB treatment? Few studies have been conducted in low-endemic, high-income settings. By exploring views and experiences in a high-endemic, low-income setting versus a low-endemic, high-income setting we may identify factors that serve as common challenges and potential solutions.

1.6 Case one: Addis Ababa, Ethiopia

In 2001-2002, Addis Ababa had about 95 % coverage of DOTS in existing governmental health facilities. TB treatment involved daily clinic attendance for two months (the intensive phase), followed by a period of six months during which medicines were collected once or twice a month (the continuation phase). In 2001-2002, there had been few studies exploring patients or health workers perception or management of TB in Addis Ababa, Ethiopia. One study examining ethno-medical knowledge and practices related to TB in a rural community in southern Ethiopia, found that the symptomatological concepts coincided with biomedicine, while local explanatory models referred to causal factors unrelated to the TB bacilli (Vecchiato, 1997). A quantitative study in Addis Ababa found that diagnostic delay was associated with patients' inadequate knowledge of TB symptoms and treatment (Demissie et al., 2002). Another quantitative study in Addis Ababa, conducted before the implementation of DOTS, found "social problems" and "feeling of improvement" to be important causes of treatment interruption (Demissie & Kebede, 1994). Quantitative studies from rural areas (conducted both before and after our study) have suggested that between 6 % and 20 % of patients interrupted treatment due to long distances to the health facilities, poor awareness about the disease and the treatment length, side effects, and lack of family support (Getahun & Aragaw, 2001; Michael, Belachew, & Jira, 2004; Shargie & Lindtjorn, 2007; Tekle, Mariam, & Ali, 2002). Studies conducted both before and after our study found that most TB patients interrupt in their third or forth month of the treatment (Demissie & Kebede, 1994; Tekle et al., 2002; Shargie & Lindtjorn, 2007).

To our knowledge, the studies on diagnostic delay and treatment interruption in Ethiopia have not been explored further in qualitative research. In general, few studies have used qualitative methods to explore TB patients' or health workers' views and experiences during different phases of the disease and the long treatment regimen. On the basis of the existing knowledge at the time of our study we found a need to explore, in-depth, how patients and health workers perceived TB and the related treatment. There was a need to explore the meaning of what seemed to be important quantitative variables (such as "social support"), how different variables were interrelated, and how and at what time in the treatment regimen they had a decisive influence. The WHO (2003, p.129) has emphasized that an important research area is identifying time points in the treatment that are of importance for different types of adherence strategy.

1.7 Case two: Oslo/Akershus, Norway

In Norway, new regulations for TB control were introduced in 2002, and the corresponding national guidelines introduced five components similar to the components of the WHO's DOTS strategy. DOT was implemented as a principle in 2003, and is to be used in all patient cases without prior selective appraisal. Knowledge regarding patients' and health workers' perception and management of TB in low-endemic countries is limited. Most studies on diagnostic delay and treatment adherence have been conducted in high-endemic countries. The only qualitative study on diagnostic delay from a low-endemic society (Wales) concluded that general practitioners (GPs) are important in diagnosing TB. Low clinical suspicion, lack of continuity of patient care, time constraints, suboptimal communication between the doctor and the patients, combined with atypical presentation could cause diagnostic delay (Metcalf, Davies, Wood, & Butler, 2007). Some studies have tried to understand management (adherence) of treatment by examining patients' and health workers' experience with DOT in low-endemic countries. One study, from New York, examining patient satisfaction with the DOT program, found that even if provision of enablers and incentives were given only about half of the patients expressed positive views. Those that were positive emphasized the supportiveness from the staff, describing them as "caring" and "wanting to help"; indicating the importance of personal involvement by staff members (Davidson, Smirnoff, Klein, & Burdick, 1999). A study based on interviews with 19 professionals, involved in TB control from various parts of the world, found that many of the informants thought that the role of the DOT provider should transcend the actual observation of a patient swallowing the medication. Participants from high-income settings in particular saw DOT as a continuous process of negotiation with emphasis on each patient's specific needs and choices (Macq, Theobald, Dick, & Dembele, 2003).

A quantitative study in Norway, based on data from the National TB Registry, clinical case notes from hospitals, and referral notes from primary health care providers, found a median total delay of 63 days from the onset of symptoms to initiation of TB treatment (Farah et al., 2006). The delay was primarily attributed to doctors not initiating TB specific examinations despite symptoms suggesting TB (Farah et al., 2006). There was little information about the causes of

patient delay. Another study from Norway showed that the total treatment result for 1996-2002 was slightly below the WHO's defined target (85 %). Of 655 patients treated for TB the total treatment success was 83 %. 22 patients (3 %) interrupted treatment, 58 patients (9 %) died and 26 (4 %) were expelled or moved out of the country (Farah et al., 2005). The latest published treatment results are from 2004 and show a completion rate of 86 %. Of 302 patients reported with TB in 2004, 10 (3, 3 %) interrupted treatment and 6 (2 %) patients left the country. Of 194 patients with lung TB, 84 % completed treatment, which is similar to previous years (Winje, Brantsæter, Heldal, & von der Lippe, 2006a). In 2005, the Norwegian Directorate of Immigration, in cooperation with Norwegian health authorities, decided that asylum seekers diagnosed with TB are not to be sent out of the country as long as they are treated for TB. Thus, a structural barrier to TB treatment may have been eliminated.

There has been no qualitative study exploring perception and management of TB symptoms, or perception and management of TB treatment, neither in the pre- or post DOT(S) era in Norway. On the basis of the existing knowledge we set out to explore patients' experiences with the diagnostic process, and patients' and health workers views' and experiences in relation to the practice of DOT.

2. Aims of the study

The overall aim of the study is to explore how patients and health professionals perceive and manage TB symptoms and treatment in a high-endemic and a low-endemic setting, with the specific aims to:

- Explore how symptoms of TB are perceived and managed from the onset of symptoms and during the course of treatment in Addis Ababa, Ethiopia.
- Explore enablers and barriers in the management of TB treatment during the first five months of treatment in Addis Ababa, Ethiopia.
- Explore experiences of being diagnosed with TB among African immigrants in Norway, with a view to factors associated with diagnostic delay.
- Explore patients' and health workers' views and experiences with TB treatment (DOT) in Norway.

3. Material and Methods

3.1 Ethiopia - country profile

Ethiopia is located on the Horn of Africa. The country constitutes a total surface area of 1.1 million square kilometers. The population in 2006 was estimated to be about 81 million, and consists of different ethnic groups (WHO, 2009d). The Oromo (32 per cent) and Amhara (30 per cent) are the largest ethnic groups, followed by the Tigre (6 per cent), Somali (6 per cent), Southern ethnic groups (10 per cent), and other smaller ethnic groups (16 per cent). The languages spoken include Amharic, Tigrinya, Oromigna, different Southern languages, Somali, Arabic, local dialects and English. English is the major foreign language taught in schools. 45 per cent of the population is Orthodox Christian, 40 per cent are Muslim, 10 per cent are Protestants, 4 per cent are animists, and 1 per cent follow other religions. The major industries are agriculture and animal husbandry (80 per cent), government and services, and industry and construction. Ethiopia is one of the poorest countries in the world, and was ranked 171 out of 182 countries in the Human Development Report 2009 (United Nations Development Programmes [UNDP], 2009). Life expectancy at birth m/f (years) is 55/58. In 2006, the total expenditure on health per capita was (Intl \$, 2006): 22 (WHO 2009d). Recurring droughts, environmental degradation, insecurity related to conflict, poor access to health services, and persistent price hikes for staple foods make Ethiopia constantly vulnerable to nutritional and health crises.

3.2 Norway - country profile

Norway is located in northern Europe. The country constitutes a total surface area of 385,155 square kilometers. Per 2006, the population consisted of approximately 4.7 million people, the population density being one of the lowest in Europe (WHO, 2009e). Among ethnic Norwegians 90 per cent are considered Christian (Evangelical Lutheran), and the language spoken is either Bokmål (influenced by Danish) or Nynorsk (new Norwegian). Sami, spoken by an ethnic minority group, is also an official language in some districts. The major industries are oil and gas, fisheries, manufactured goods, machinery and transport. Immigrants and Norwegians-born to immigrant parents constituted nearly 508 200 persons (10.6 per cent) of Norway's population in 2009. Additionally, 230 000 persons have one Norwegian and one foreign-born parent. Most immigrants and Norwegians-born to immigrant parents live in Oslo (relative and

absolute figures). According to Statistics Norway [SSB] (2010a), 152 100 (25 %) of Oslo's 575 500 inhabitants were immigrants or Norwegians-born to immigrant parents in 2009. The largest immigrant groups are from Poland, Pakistan, Sweden, Iraq, Somalia, and Germany. Between 1990 and 2008, 377 000 non-Nordic citizens were granted residence in Norway. Of these, 24 % came as refugees, 24 % came as labor immigrants and 11 % came in order to undertake education. A large group (23 %) came to Norway due to family reunification, and 17 % were granted residence because they had established a family in Norway (SSB, 2010b). People from Somalia and people from Ethiopia are among the groups that have the shortest residence in Norway (SSB, 2007; SSB, 2010c). There were almost no Ethiopians in Norway before 1985 (SSB, 2007). The first refugees from Somalia came in mid-1980. After the dissolution of the Somali state in 1991, the number of refugees from Somalia has increased (SSB, 2010c). The structure of these two population groups is typical of those with short residence; a majority is refugees; many are young adults, and the majority is men (SSB, 2007, SSB, 2010c). Norway is one of the richest countries in the world, and ranked first in the Human Development Report 2009 (UNDP, 2009). Life expectancy at birth m/f (years) is 78/83. Figures from 2006 show that the total expenditure on health per capita was (Intl \$): 4,521 (WHO, 2009e). The public sector is the main source of health funding in Norway. In 2005, about 84 per cent of health spending was funded by public sources (SSB, 2006).

3.3 Theoretical frameworks

The study was initially theoretically influenced by behavioral sociologist Howard Becker's work. Becker has reviewed models and theories seeking to explain individuals' adherence to medical treatment. He found that different theories and models converge on many of the same elements. In general, these theories and models conclude that there will be some predisposing factors that together with certain enabling and supportive factors will lead patients in different directions when making choices about treatment (Becker & Maiman, 1975; Becker, 1990, p. 5-37). Predisposing factors include (among others) health beliefs and attitudes towards the disease, the related treatment, and the health services. These health beliefs include both general health beliefs (as concern about health matters in general, willingness to seek and accept a certain medical direction) and specific health beliefs (as perceived susceptibility to the disease, belief in diagnosis, perceived severity of the condition). Following Becker, these factors in isolation

will seldom be directly responsible for the continuous use of health services, but may influence how motivated patients are for initiating and completing a long treatment-regimen. The same factors can also indicate what type of information and support is needed from health personnel. However, as emphasized by Becker, even though some patients are predisposed to use certain health services, some means must enable them to do so. Enabling factors such as availability of relevant health services, and factors related to accessibility; use of time, use of money for transport or treatment, long waiting hours, loss of possibility to work, difficult appointment-times or poor treatment by health personnel are decisive factors. Perceptions or experiences of social, psychological, physical or economic costs of the recommended behavior will, through initiation of treatment to its completion, be influential. This influence can be modified through support from health personnel, family, friends, and in some cases the neighborhood. This is particularly relevant if the disease is stigmatizing in nature. Social support or social pressure can also stimulate certain behavior in cases where the diseased person is not ready to take appropriate health action.

Following Becker and Maiman (1975), and Becker (1990), and the Health Belief Model (HBM), the amount of health services being utilized by a person will be a function of the predisposing, enabling and supportive factors present over time. The combination of different factors will continuously be interpreted and evaluated and the “sum” of perceived negative and positive aspects of treatment may lead a patient in different directions, making different choices, in different stages of treatment.

Becker’s synthesized perspective views health behavior change as a rational appraisal of barriers and benefits associated with action. The assumption that individuals behave in such a rational or conscious way is the source of one, of several, critiques of his perspective. Another objection is that the relationship between the described variables is unclear; there are no definitions of the individual components and no formulation of rules regarding combinations. It is assumed that the different variables are not moderated by each other and that they have an additive effect (Munro et al., 2007b). The HBM has also been criticized for a lack of evidence to support the belief-behavior relationship, and that it has too much focus on individual factors compared to socio-economic and environmental factors. It has been suggested that the model encourages victim blaming because of its strong focus on the individual’s part in

determining behavior (Roden, 2004). In a review of health behavior theories and their usefulness in promoting long-term medication adherence for TB and HIV/AIDS, the authors, Munro et al., conclude that there is little empirical evidence on the effectiveness of different theories in promoting adherence (Munro et al., 2007b). However, they suggest that several models and theories have the potential to contribute to our understanding of adherence behavior. The authors encourage future research that will build on theories, and that to a further extent include issues over which individuals have no control. Another point being raised by the authors is the need to identify theories of health behavior change that are suited to explain adherence to long-term medication. Even though Becker has been criticized for a lack of focus on structural barriers, we have read and used Becker in the sense that we interpreted the term “enabling” factors as including a focus on structural barriers such as lack of availability and accessibility of relevant health services. There are several components within the HBM, and in 1990 Becker added the concept “self-efficacy”, which involves expectancies of performing a specific behavior in a specific situation. Our study is particularly inspired by the components that concern perceived vulnerability to and severity of the disease as well as perceived benefits and costs of treatment.

This study was also inspired by Christensen-Szalanski and Northcrafts’ (1985), suggested effect of time *per se* on adherence behavior. Christensen-Szalanski and Northcraft argue that treatment adherence is a dynamic process in which costs and benefits accrue at different rates over time. They claim that models commonly used to explain adherence-behavior, such as the HBM, have not taken into account the passage of time as a factor that can modify perceptions of costs and benefits associated with treatment compliance. Christensen-Szalanski and Northcraft point to the importance of understanding patients’ temporal perception of costs and benefits, and how temporal perceptions may be influenced by delayed benefits and accrued costs. Within this theoretical scenario, a decision of interrupting treatment, which may seem incomprehensible, may have been shaped by past struggles and accrued cost. Therefore, these decisions should not necessarily be understood as a response to an immediate change.

Kleinman’s (1980) conceptual division of health care systems has also influenced this study. According to Kleinman (1980, p.50-70), health care systems consist of three partly overlapping sectors: the popular sector (individual, family

and community beliefs and activities), the professional sector (the organized and institutional parts of health care) and the folk sector (sacred or secular types of folk medicine). Kleinman (1980) conceptualizes illness and disease as socially constructed “explanatory models” which represent patterns of thoughts that provide answers to questions regarding etiology, symptoms, cause, course and treatment. Thus, the health care system includes people’s beliefs and their behaviors, in which to a great extent are governed by cultural rules (Kleinman, 1980, p.26). According to Kleinman, the beliefs and behaviors that constitute the different activities are influenced by particular social institutions (e.g. clinics), social roles (e.g. sick-role, healing role), interpersonal relationships (e.g. doctor-patient relationships, social network relationships), interaction settings (e.g. doctors office), economic and political constraints (accessibility, availability) and a number of other factors. Illnesses and their variety of responses form different components of the health care system, and are systematically interconnected (Kleinman, 1980, p.26). Kleinman uses the term “clinical reality” to describe “the beliefs, expectations, norms, behaviors, and communicative transactions associated with sickness, health care seeking, practitioner-patient relationships, therapeutic activities, and evaluations of outcomes” (Kleinman, 1980, p.42). The “social reality” is the part of reality that expresses different clinical phenomenon, but this part of the reality is itself constructed by the clinical reality (Kleinman, 1980, p.42).

Individuals, as well as the various agents in the three sectors of the health care systems, may perceive and explain similar symptoms differently. In many cases explanatory frameworks may overlap. Research suggests that models that are traditionally invoked in the popular or folk sector may also prevail in the professional biomedical sector (Helman, 1978; Scheper-Hughes, 1988). Further, an illness may inspire different explanatory models as symptoms develop over time or as a response to separate approaches towards the treatment of symptoms and the treatment of cause (Good, 1994; Robinson, 1990). Both Kleinman (1980) and Good’s work (1994) represent the “meaning-centered approach” in medical anthropology. Kleinman (1997) has criticized his own concept (explanatory models) for neglecting the dimension of suffering. He points to the importance of acknowledging social suffering as a dimension that includes the consequences of

war, famine, depression, disease, suppression, and torture – all factors resulting from political, economic and institutional power (Kleinman, Das, & Lock, 1997).

This study has also been influenced by Paul Farmers work and ideas (1997; 1999). In the same way people try to adapt to their lived world within given socioeconomic incentives and constraints, they will adapt and rationalize behavior related to the medical sphere. To be able to understand more about people's movements within the different parts of the health care system, structural barriers, and how such barriers limit patients' ability to access, maintain and complete therapy, need to be explored.

The study has, in its later stages, also been influenced by Foucault (1975), and his perspectives on how infectious diseases are being managed. Foucault argues that the idea of keeping everything within the borders of what is "normal" is a driving force in modern societies. The primary function of modern disciplinary systems is to correct abnormality by regulating behavior. Infectious diseases may induce fear of chaos in the population, and this fear is managed by imposing discipline and order. A society may respond to an abnormality, like an infectious disease, by declaring a "state of emergency" with subsequent restrictions or withdrawals of individual rights. In public health discourse, members of the middle class have historically been portrayed as possessing the valued qualities of self-denial and self-efficacy, while individuals from the working class are seen as lazy, dirty, immoral and incapable of resisting their urges. Disciplinary measures to impose order have subsequently, first of all, been directed toward less-privileged members of society (Foucault, 1975; Lupton, 1995; Coker, 2000).

3.4 Addis Ababa: Participants and study design

The empirical data in this part of the study were generated in semi-structured interviews and focus groups in October 2001 and March 2002, with a sample of participants diagnosed with TB, their relatives and a group of health personnel. A sample of 32 respondents; 23 TB patients, five health personnel and four relatives were recruited for in-depth interviews. We recruited an additional 11 participants for focus group discussions. Four of these had previously attended an in-depth interview. We included TB patients who were attending TB treatment and TB patients who had interrupted TB treatment. Since the study initially sought to explore reasons for non-adherence we considered to include only patients that had

interrupted treatment. However, we decided that only including patients that had interrupted treatment could result in a response bias. Patients that have defaulted from treatment might fear being labeled or stigmatized, and provide answers focusing on defending or “rationalizing” their actions. Additionally, data obtained about previous decisions and events may be influenced by recall bias. By including a group of regular TB patients, and following them over time, we sought to reveal what types of enablers and barriers were important during treatment, and in what way the identified factors interacted in different stages of treatment. We recruited 10 newly diagnosed TB patients, five men and five women, aged 18 to 67 years, on the basis of a purposeful sampling strategy in which we sought to ensure variation related to educational background, gender and age (table 1). The participants belonged to different ethnic groups, but almost all were Orthodox Christians (one Muslim, one Catholic). All 10 participants had been diagnosed with pulmonary TB. Potential participants were approached with written information about the study by nurses at Woreda 23 Health Clinic; a centre for TB diagnosis and treatment. Two patients declined to participate because they were too ill.

We recruited 11 TB patients, six men and five women, aged 20 to 60 years, which had interrupted treatment. Seven of these participants had been diagnosed with pulmonary TB and four had been diagnosed with extra-pulmonary TB (table 1). There were difficulties with tracing patients who had interrupted treatment, due to lack of, or incorrect, addresses. St Peter’s TB Specialized Hospital Outpatient Service, a hospital which offered diagnostic and treatment services, and Kebele 16 Health Post, which provided TB treatment but was without diagnostic facilities, were included for the purpose of recruiting patients who had interrupted treatment. The three research sites were chosen based on advice from local researchers at Armauer Hansen’s Research Institute (AHRI) and from the WHO’s TB/Leprosy advisor at the Ministry of Health in Ethiopia. The sites were considered to be “typical” DOT clinics, but they were also chosen because they represented diversity being located in different areas of the city. We traced 11 patients that had been on treatment for at least two weeks, and had interrupted treatment for more than six consecutive weeks at the time of contact. All eleven patients agreed to participate in the study. The National Tuberculosis and Leprosy Control Program (NTLCP) restricts its definition of defaulters to patients who have attended

treatment for at least four weeks and have been absent for at least eight consecutive weeks or for a cumulative period of 12 weeks. (The definition of a defaulter, used by the WHO, is a patient whose treatment was interrupted for 2 consecutive months or more. (WHO, 2007). We considered that the strict use of the NTLCP's definition would exclude the experiences of patients that, due to unknown reasons, had interrupted treatment within the first four weeks. By including patients from this group we were able to explore these patients' experiences. Some of our participating patients in this group do thus not meet the formal definition of a defaulter as set by the NTLCP.

Table 1: Characteristics of 10 patients undergoing treatment and 11 patients who had interrupted treatment who were interviewed individually

Characteristic	Undergoing (n = 10) No.	Interrupted (n = 11) No.
<i>Gender</i>		
Male	5	5
Female	5	6
<i>Age</i>		
< 25	3	2
26–35	6	6
> 36	1	3
<i>Education</i>		
Partly illiterate/illiterate	1	4
1–6 years	3	3
7–10 years	1	2
11–13 years	5	2
<i>Occupation</i>		
Daily labourer*	2	3
Civil servant	2	1
Private sector	3	4
Other	3	3

* Person who is not employed on a permanent basis, but who may meet at a regular point every day to compete with others to be hired for the day.

To investigate treatment adherence from perspectives other than the patients, we included other groups of informants. Two relatives of patients that had died or were terminal after interrupting treatment, and two relatives that escorted severely

ill patients to the clinic daily, were interviewed. Two TB patients on re-treatment were also interviewed. In-depth interviews were additionally conducted with two nurses and one doctor from Woreda 23 Health Centre, one nurse from Kebele 16 Health Post and one nurse from St Peter's TB Specialized Hospital Outpatient Service. These individuals were recruited because they were managing TB patients on a full-time basis in the same clinics where we had recruited patients.

At the end of the study we recruited TB patients undergoing TB treatment for focus group discussions. Focus group participants were recruited by the first author and the research assistant from all three clinics. Patients with different educational backgrounds were chosen, yet with adjustments to personal features and the group composition as a whole. One group consisted of five female TB patients, the other of six male TB patients. Two patients in each group were patients that had been interviewed earlier. These participants were considered to be particularly valuable informants in the sense that they had provided balanced and many-faceted perspectives.

3.4.1 Interviews

The interviews were conducted during the period from October 2001 until March 2002. 10 TB patients that were attending treatment were interviewed three times over a period of five months. The first in-depth interview was conducted two weeks after diagnosis, the second interview two months later and the third interview five months into treatment. All patients, except one who died, participated in all three interviews. A single individual in-depth interview was conducted with each of the 11 patients who had interrupted treatment. All interviews took place at locations chosen by the patients, such as in a closed room in the clinic area, the patients' homes, and in one case in the home of the researcher. The questions and answers were translated from English to Amharic or Oromo and vice versa by a local research assistant/interpreter that participated in all the interviews. The interviews lasted from two to three hours, the length being influenced by the continuous translation as well as minor discussions between the research assistant and the researcher about the meaning of different words and statements and how to proceed with the interview. My interview approach was inspired by Kvale's principles for qualitative research interviewing (Kvale, 1996, p.131-135). I used various strategies

and types of questions to structure the interview, such as introducing questions, follow-up questions, probing questions, specifying questions, and interpreting questions.

My point of departure was an interview guide that was developed as a result of a thorough literature review. The interview guide also drew inspiration from Becker's review (Becker & Maiman, 1975; Becker, 1990) to find factors associated with adherence, and Kleinman's (1980) theories on the use of different health care systems. The development of the interview guide also drew on Christensen-Szalanski and Northcraft's (1985) suggested effect of time *per se* on adherence behavior. Lastly, the interview guide drew inspiration from a debate in the research community, in particular between Barnhoorn and Farmer (Barnhoorn & van der Gest, 1997; Farmer, 1997), about which factors were most relevant in understanding the phenomenon "non-compliance". The discussion centered on to what degree themes related to patients' "health beliefs" were important in understanding non-compliance. Farmer argued that these approaches are overemphasized and that studies fail to recognize the wider influences on patients' lives such as poverty, conflict, political instability, racial and gender inequalities, all factors beyond the control of the individual.

We decided to develop the interview guide as a response to all main perspectives identified in the literature, and it was structured to cover four broad themes: 1) Symptom understanding/understanding of own vulnerability, and health related behaviour; 2) Interaction with health personnel; 3) Social support factors and; 4) Structural/socio-economic barriers (Appendix A; Appendix B).

Many of the questions in the guide were influenced by the interview guide used by Barnhoorn and Adriaanse's (1992) in their study: "In search of factors responsible for noncompliance among tuberculosis patients in Wardha District, India", which at that time was available on the internet. The aim was to explore which factors were more important from the patients' view, in what way different factors were interrelated, and whether the influence and interrelation of different factors changed during treatment. Questions in the interview guide were open-ended and developed to enable patients to respond to introductory questions related to all the main themes. Several suggested follow-up questions and probing questions were included. After each interview emerging themes and hypotheses from earlier interviews were included and explored in subsequent interviews. In the interview-guide used for the patients that were interviewed three times, each

interview generated personal questions that were to be pursued in the second and third interview.

The interviews conducted with the patients that had interrupted treatment gradually took a narrative form. The narrative method was used because we found that allowing people to tell their stories gave us more insight into the cultural framework within which the participants made sense of their actions. By the use of a narrative approach we experienced that we allowed the participants to set the agenda, to select the aspects that were important to them; and to order these aspects, in their own language, into a non-fragmented whole (Elliot, 2005, p.1-36). We began with an open question asking the patient to describe the period when s/he first felt ill, and if the answer spontaneously took form as a story we sought not to interrupt. Narrative probing was used when narrative fragments were unclear or not exhausted. The interview guide was used to check that topics were covered, sometimes leading to the inclusions of specific questions at the end of the interview. Patients who attended treatment and patients who had interrupted treatment were in general interviewed about the same themes. Part of the validation process involved identifying intersects between findings in the different groups. The interview guide that was used in the interviews with health personnel was based on the same themes as the interview guide used for patients (Appendix C). It was designed as a thematic guide and sought to explore health workers' views and experiences on topics such as barriers and enablers faced by TB patients.

3.4.2 Focus groups

Two focus groups with TB patients undergoing treatment were arranged after the in-depth interviews were completed. The focus group discussions lasted for about two hours, and were held in a room in one of the clinics. The focus groups were moderated by the research assistant, who was trained in focus group techniques and in qualitative methodology. The development of focus group questions was a result of a thorough review of all the earlier collected material. The first author was present and introduced topics related to common, discrepant or particularly interesting findings from the in-depth interviews for further exploration and validation. The research assistant had been involved in all stages of the research; enabling him to improvise; introduce new questions or adjust to subjects as they were raised. Notes were taken, and the discussions were tape-recorded and transcribed.

3.4.3 Observations

Observation was not formally included as part of the methodology and not described in the methodology section in either of the papers from Ethiopia. However, I gained valuable insight into communication and interaction patterns between health workers and patients due to considerable time observing at the clinics. The observations were not planned, but took place while sitting on a bench in the clinic area waiting to meet a patient, health personnel or my research assistant that was often late due to unpredictable public transport schedules. The DOT procedure was conducted either outside or partly outside the clinics (patients moving in and out of an open door) and the interaction between the nurses and the patients were easily observed. Interaction and behavioral patterns described by the patients that were attending daily treatment were often illustrated and confirmed during these observations. When my research assistant was present we would discuss and negotiate what we saw and he provided valuable insight into the non-verbal language in the light of the specific cultural context.

3.5 Oslo/Akershus: Participants and study design

The empirical data in this part of the study were generated in semi-structured interviews with a sample of 42 participants, of which 22 were TB patients and 20 were health personnel working with TB patients. Data collection took place between June 1st 2007 and June 30th 2008 in the city of Oslo, and the surrounding county of Akershus, in Norway. Participants were recruited through the primary health care services and from six hospitals: Ullevål University Hospital, Aker University Hospital, Akershus University Hospital, Asker and Bærum Hospital, and Lovisenberg Diakonale Hospital. Written information was sent to hospitals in Oslo/Akershus and a variety of primary health care districts. Health personnel in leading positions were subsequently contacted by the first author by phone, in order to come into contact with doctors or nurses in key positions. Some of the health personnel were recruited by snowball sampling, as participants were asked to identify potential participants who could provide relevant information. The final sample of health personnel consisted of eight men and twelve women, of whom eight were doctors (specialists in either lung diseases or infectious diseases), five were TB coordinators, two were community nurses, and five were nurses from home based services. Some of the TB coordinators and nurses that were recruited later helped us in informing and recruiting patients. We recruited a purposeful sample of

10 male and 12 female TB patients, aged 19-42, who originated from Somalia and Ethiopia (table 2).

Table 2. Characteristics of patients (n = 22)

Characteristic	No.
Country of origin	
Somalia	15
Ethiopia	7
Gender	
Male	10
Female	12
Age	
19–25 years	10
26–35 years	8
35–42 years	4
Education	
<8 years	7
8–12 years	11
13–15 years	4
Occupation	
Unemployed	7
Self-employed	1
Skilled manual	1
Unskilled manual	5
Student/secondary education	3
Non-permanent work	5

The decision to include respondents who were born in these countries was based on the epidemiological situation when the study was planned. Data from the Norwegian Surveillance System for Communicable Diseases (MSIS) showed that the number of reported TB cases in 2005 and 2006 were highest among people who originated from Somalia and Ethiopia (Winje et al., 2006b; Winje et al., 2007). We therefore considered these groups to be of particular interest to policymakers and health professionals. It was also of interest to compare perceptions and experiences within the same group (Ethiopians) in two very different contexts.

The participants that were recruited had all been notified to one of the local TB coordinators, after they had been diagnosed in a hospital and TB treatment had been initiated. During the data collection period, a total of 10 persons originating from Ethiopia and a total of 30 persons originating from Somalia were diagnosed with TB in

Oslo/Akershus. Each time a new TB patient from Somalia and Ethiopia was notified, the TB coordinator or nurse would inform me (MS). We recruited 22 participants on the basis of a purposeful sampling strategy in which we sought to ensure variation related to educational background, gender and age. Potential participants were approached with written information about the study by a TB coordinator or a nurse. Participants then contacted the researcher by phone, or the researcher contacted patients if they had given their consent. Two patients declined to participate stating they did not want to share their experiences with those other than family. The sample size of 22 patients was a result of saturation in the data, as we found that additional interviews yielded little new information. Most of the participants from Ethiopia were Orthodox Christians, and all the participants from Somalia were Muslim. The duration of stay in Norway varied from six months to 16 years (mean stay was seven years). Half of the participants (11 patients) had been diagnosed with pulmonary TB and the other half (11 patients) with extra-pulmonary TB. At the time of the interviews, 16 patients were undergoing TB treatment. Five patients had recently completed treatment. One patient had interrupted treatment. All participants gave their written consent to participate in the study.

3.5.1 Interviews

The interviews took place between June 1st 2007 and June 30th 2008. All the in-depth interviews were carried out by me (MS). The patient interviews lasted from one to three hours and were tape-recorded. They took place in locations chosen by the patient, such as in the patient's home or in a suitable room in one of the university buildings. Most interviews were conducted in Norwegian. Some interviews with patients were conducted in English, depending on the patients' language skills and preferences. One patient was interviewed with the assistance of an interpreter. Eight patients were interviewed twice, in order to assess whether their perspectives or experiences had changed throughout treatment, and to explore themes that appeared to be unclear or ambiguous. The health personnel interviews lasted from one to two hours and were tape-recorded. They took place either at the locality where the participant worked or in a room in one of the university buildings.

My interview approach was inspired by Kvale's principles for qualitative research interviewing (Kvale 1996, p.131-135). I used various strategies and types of questions to structure the interview, such as introducing questions, follow-up questions,

probing questions, indirect questions, silence, and interpreting questions. My point of departure was an interview guide that was developed as a result of a thorough literature review and experiences, inspiration sources and findings in previous research (paper I and paper II). The interview guide for patients covered five major themes: (1) Symptom understanding/understanding of own vulnerability, and health related behavior; (2) interaction with health personnel; experiences related to the diagnostic process; (3) information and understanding of the disease; 4) social support factors and 5) perceptions and experiences related to treatment (DOT) (Appendix D). Questions in the interview guides were broad and open-ended and formulated with the intention to enable participants to describe and emphasize what they considered to be significant. I did not follow the interview guide strictly, but aimed at creating an atmosphere where the participants were encouraged to talk freely about their views and experiences. In some interviews participants started to answer the first question (“Can you tell me about the period when you first felt ill?”) by telling their stories, and whenever a participant preferred to express himself through a full story s/he would rarely be interrupted. Structuring questions were sometimes used to interrupt long reflections on parts that were irrelevant to the topic of the investigation (Kvale, 1996, p.134). The interview guide was used to check that the main topics were covered. In addition, themes that emerged during the data collection were systematically written down and explored in subsequent interviews. Socio-demographic data was taken at the end of the interview.

The interview guide for health personnel covered three broad themes: (1) experiences and reflections concerning TB related work and strategies on a system level; (2) experiences and reflections concerning TB related work on an individual level; (3) reflections concerning ethical aspects of the treatment system (DOT) (Appendix E). Even if there were some predetermined themes that were to be covered, the interviews with the health personnel often took form as an informal conversational interview adjusting to the immediate context and the experiences of the different professions (Ulin, Robinson, & Tolley, 2005). Relevant themes that emerged during the data collection were systematically written down and explored, when relevant, in subsequent interviews.

3.6 Differences in sample and methods

There were differences in the sample and the methods employed in the two cases included in this study. In both Ethiopia and Norway we recruited patients through health workers. In both studies we included participants from different clinics/hospitals and we interviewed both patients and health workers. The total sample of participants in the Ethiopian study was 39 (including the new participants in the focus groups), while the total number of participants in Norway was 42. The number of health workers included from Norway exceeded the number of health workers included from Ethiopia. Including a higher number of health personnel gave a broader and more thorough exploration of this group's views and experiences. Data provided by health workers became an important source of validating and exploring some of the data provided through the interviews with the patients. In Ethiopia, we included different types of participants, such as patients' relatives, and different types of patient groups (patients on regular treatment, patients on re-treatment, and patients that had interrupted treatment). The inclusion of different participants provided a deep and many-faceted insight into the perspectives and experiences expressed by patients. The use of focus groups towards the end of the study gave us an opportunity to explore and validate important findings even further.

The most important methodical difference between the two cases is that the sample of patients in Norway only included one patient that had interrupted treatment. In Ethiopia we managed to include 11 patients that had interrupted treatment, and subsequently this group's experiences were explored more in-depth. The Norwegian data provides insight into the burdens of TB treatment, whereas the Ethiopian material provides insight into the actual causes of treatment interruption. The data provided by the patients that had interrupted treatment were to some extent also validated by the data provided by patients that were interviewed three times over a period of five months. Each of these interviews explored what types of barriers and enablers were perceived as particularly relevant in a specific period of treatment. Thus, these data provided insight into factors that can help explain adherence to long-term medication.

3.7 Interviewer's role, background and perspectives

3.7.1 Case one: Addis Ababa, Ethiopia.

In the interview setting I was particularly conscious to create an atmosphere where the participants would be encouraged to speak freely about their views and experiences. I presented myself as a “researcher with an interest in how tuberculosis patients perceive their disease and the medical treatment”. In the consent form I informed participants that I was a nurse and that the study was part of a masters degree in international community health at the University of Oslo, Norway. I presented my research assistant as my interpreter and assistant, and informed the participants of his background as a sociology student at Addis Ababa University. I explained the aim of the study and said that the information they gave me could be helpful in improving TB related health services. I intentionally emphasized the interest in TB from a social science perspective to remove the focus from my role as a health worker and to encourage patients to reflect on their disease and treatment beyond a medical perspective. I underlined that the information they gave me and my assistant would be treated confidentially. Even though I sought to under communicate my role as a health worker, many patients asked questions related to the disease and treatment. In such cases I emphasized that I was not an expert on the disease or the medication and encouraged them to contact a nurse or doctor. In certain cases, such as when patients told me about severe side effects, I facilitated direct contact with one of the health workers.

On the basis of readings and discussions with local students and researchers I learned that there is (for different reasons) a general fear of authority among many Ethiopians. Health personnel in particular are highly respected and many patients expressed that they did not dare approach a health worker to ask questions. In my role as a foreign researcher I decided to communicate the differences I represented. For example, when patients greeted me in a very polite form (by holding their left arm on upper right arm while bowing) I would greet them in the same way. Most participants did not seem to expect me to greet them this way and many started to laugh when I adapted the same approach. This situation gave me the opportunity to explain to them that I was used to greeting everyone in the same way, and to consider people as equals. The approach felt honest and right and it enabled me to define myself in a way that was different and

surprising for the participants. To reduce the distance between myself, the research assistant and the participants we were always careful in our non verbal communication such as the way we dressed, talked and behaved. Entering the clinic by foot or public transport was one such means.

Due to the presumed power imbalance in the interview situation, I was concerned that participants would seek to tell me what they thought I wanted to hear. During the interviews I emphasized that I was interested in *their* point of view. Over time, in particular with the group of participants that were interviewed three times, my experiences reassured me that participants felt safe enough to express what they felt was important. Those that expressed tension or insecurity in the first interview became increasingly relaxed and open throughout the subsequent interviews. Even in cases where participants were introduced to direct, and to some extent, leading questions, they would often redirect the question, argue why, and often answer the opposite of what I expected. Some of the participants told us that they had shared issues they had never shared with anyone before. Some of the women told us that they were surprised finding themselves talking openly to a man (the assistant) about sensitive issues like sexuality.

An important reflection, however, is how and to what degree my presence influenced the views and behavior of the participants. This is a difficult question to answer, because many unknown mechanisms may have been in play. What sometimes seemed clear was that the participants, through my questions and probes, were introduced to certain values and perspectives, and the relevance of these values and perspectives may have been redefined for them. An example of this were the questions about when and how patients got information about TB, and whether or why they had not asked questions about their disease and treatment. Some patients told me in the second or third interview, that as a result of the meeting with me, they had approached the health personnel asking some of the questions they had wanted to ask for a long time. In this way, not only participants' views may have been affected, but also their behavior.

Working with an interpreter was the challenge I was most concerned about before entering the field. I systematically worked to prevent errors or biases due to misinterpretations or misunderstandings. The interview guide was translated back

and forth three times with different results. The final result was a negotiated version based on an agreement between the research assistant and myself. Before we started the data collection the research assistant and I discussed the protocol, relevant literature, and simulated interviews. During this process we thoroughly discussed the aim of the study, the questions that were to be answered through the study, and important words and concepts that were to be used (internal validity). We spent time together in local museums, the university area, and in the city surroundings. I was introduced to important historical and political events, cultural norms and features, relevant books and articles, all important parts of the context in which the data was to be interpreted. As a result of the time we spent together, we became increasingly familiar with each others preconceptions, enabling us, to a further extent, to understand and contextualize our immediate interpretations and responses.

My motive for engaging in this research project was an interest in understanding more about patients' and health workers' views and experiences of TB and management of the disease. Malinowski argues that "preconceived ideas are pernicious in any scientific work, but foreshadowed problems are the main endowment of the scientific thinker" (Malinowski, 1922, p.8-9). Foreshadowed problems are statements of specific research questions or problems that provide a focus for the research. Foreshadowed problems help identify what factors to consider without specifying anticipated results. My professional background is nursing with an academic degree in anthropology, and a master's degree in international health. Due to this diversity, I brought with me a variety of preconceptions and "foreshadowed problems". I was inspired by different works in medical anthropology (Kleinman, 1980; Farmer, 1999), social psychology (Becker & Maiman, 1975; Becker, 1990), epidemiology (Reichman & Hershfield, 2000) and by interdisciplinary approaches to TB (Porter & Grange, 1999). My aim was to bridge different perspectives and theories and I assumed that a comprehensive understanding could help facilitate a better management of TB patients at the clinical, or even the global level.

My research assistant, a local man aged 22, with a middle-class background, holding a bachelor in sociology, also brought with him a variety of preconceptions. He was inspired by his sociology studies, knowledge from a recent

participation in a local study on HIV/AIDS, and from voluntary work nursing patients in public hospitals. He was strongly engaged in the society he lived in, and he was a politically active student. It is obvious that his way of understanding the society and the culture we were part of influenced me to a great extent. The views and experiences that we sought to interpret and understand became a reflected and negotiated version of two people's frames of reference.

3.7.2 Case two: Oslo/Akershus, Norway

In this part of the study I was also conscious to create an atmosphere where the participants would be encouraged to speak freely about their views and experiences. I presented myself as a “researcher with an interest in how tuberculosis patients perceive their disease and the long medical treatment”. In the consent form I informed participants that I was a nurse and that the study was part of a PhD program at the University of Oslo, Norway. I told the participants that I had conducted a similar study in Ethiopia. This was a good way of “breaking the ice” when meeting participants from Ethiopia. I explained the aim of the study and said that the information they gave me could be helpful in improving TB related health services in Norway. As with the previous study I intentionally emphasized the interest in TB from a social science perspective to remove the focus from my role as a health worker. I underlined that the information they gave me would be treated confidentially. Even though I sought not to focus on my role as a health worker, some patients asked questions related to the disease and treatment. In such cases I emphasized that I was not an expert on the disease or the medication, but if I felt able I answered some questions at the end of the interview. Otherwise, I encouraged them to contact the TB coordinator or the hospital doctor.

I entered the second part of this study with changed preconceptions due to the experiences and knowledge gained from the study in Ethiopia. One of the insights I brought with me from Ethiopia, was that the implementation and practice of DOT involved many challenges for patients. Acquiring this knowledge inspired a more nuanced view of the existing TB treatment system, and the analysis of the Norwegian data was done with a more critical view than during the first part of the study.

3.8 Analysis

3.8.1 Case one: Addis Ababa, Ethiopia

To reduce sources of misunderstandings and misinterpretations, key words, broader concepts and units of meaning were constantly discussed before, during, and after the data collection. After each interview the research assistant and I listened to the tape-recorded interview and thoroughly discussed and clarified the content. I took notes while listening, capturing the main essence of the answers provided by each of the participants. In collaboration with the assistant, the cultural content was “decoded” and contextualized, clarifying notes were added and main themes and issues to be explored in subsequent interviews or focus groups were systematically written down. Personal issues, and unclear or ambiguous issues, were systematically written down to be pursued in the second and third interview. Conceptual maps were used to visualize associations between potential categories and concepts. The research assistant transcribed and translated (close to verbatim) each interview and focus group discussion after we had discussed and negotiated the content. After the transcription the interview was read by me, which encouraged minor discussions and clarifications.

All transcriptions were manually coded within a defined coding frame. The coding frame was developed on the basis of four broad themes identified by the literature, but was informed by themes and issues emerging from the material. For example, themes like religion and sexuality, initially not included as questions or probes, developed to be important themes throughout the study. Data concerning different factors related to how patients and health personnel perceive and manage TB were used for systematic text condensation in accordance with the principles of Giorgi’s phenomenological analysis (Giorgi, 1985), as modified by Malterud (Malterud, 1993). The analysis followed these steps: (i) reading all the material to get an overall impression; (ii) identifying units of meaning that represent different factors related to how patients and health personnel perceive and manage TB and coding for these; (iii) condensing and summarizing the content of each of the coded groups; and (iv) integrating the insights from the condensed meaning units into generalized descriptions that reflect apparently significant factors.

The findings and analysis were summarized and accounted for in an analysis document that was used as a basis for writing and revision of the two first manuscripts

(paper I-II). I wrote a memorandum which included demographic information on each participant, observations and reflections from each interview, and a description of main issues that emerged in each interview. These memorandums were helpful tools during the analysis and I consulted them if I needed any contextual information about excerpts or quotes used as illustrations. Further, the memorandum enabled my supervisors to read about each of the participants referred to in the paper.

3.8.2 Case two: Oslo/Akershus, Norway

In the Norwegian part of the study I transcribed the tape-recorded interviews verbatim. Most of the transcriptions were done immediately after the interview. During the process of transcribing the interviews I wrote a memorandum which included demographic information on each participant, observations and reflections from each interview, and a description of the main issues that emerged in each of the interviews. Main issues were transferred to a separate word document suggesting potential codes and categories. As in the previous study, the memorandums were helpful tools during the analysis and I consulted them if I needed any contextual information about excerpts or quotes used as illustrations. The qualitative software NVivo 7 was used to organize the material (QSR International, 2009). My main supervisor and I independently read half of the transcripts and developed a coding frame for the analysis. I coded all the transcripts, while both my supervisors contributed in the analysis. Data regarding views and experiences related to TB and treatment (DOT) were identified among patients and health personnel and were used for systematic text condensation in accordance with the principles of Giorgi's phenomenological analysis (Giorgi, 1985), as modified by Malterud (Malterud, 1993). The analysis followed these steps: (i) reading all the material to get an overall impression; (ii) identifying units of meaning about views and experiences concerning how patients and health personnel perceive and manage TB and coding for these; (iii) condensing and summarizing the content of each of the coded groups; and (iv) integrating the insights from the condensed meaning units into generalized descriptions that reflected significant factors. The findings and analysis were summarized and accounted for in an analysis document that was used as a basis for writing and revision of the third and fourth manuscripts (paper III-IV). Quotes from the interviews were translated from Norwegian to English by me (MS) in the process of writing the articles.

3.9 Ethical considerations

Ethical approval for the Ethiopian part of the study was obtained from the Regional Committee for Medical Research Ethics, Region West, Norway (reference: 071.01), and the National Ethical Clearance Committee in Ethiopia (reference: RDHE/43-42/2001). All participants were informed about the purpose of the study, and that they could withdraw from the interview and the study at any time without giving a reason and without penalty to their treatment. Informed, oral or written consent was sought in all cases. De-identification and confidentiality were ensured by using numbers and fictitious names to describe and identify patients.

There is an inevitable power imbalance between health personnel and patients, and the use of health personnel to help recruit patients to research may cause patients to feel pressured to participate due to a feeling of duty or because they depend on the good will of the health personnel (Richards & Schwartz, 2002). This inter-relationship and power imbalance between health personnel and patients has been discussed earlier. We sought to prevent such pressure by instructing the nurses in a way that would ensure ethical concerns during recruitment of patients. At each interview we thoroughly went through the consent form, repeating the aim of the study, that the information they provided would be confidential, and that they could withdraw at any time. In this way we considered the consent as an ongoing process instead of a one-off event (Richards & Schwartz, 2002).

Qualitative interviews, which allow people to speak in their own terms, can potentially be therapeutic. However, the interview can also lead to exploitation and harm. The researcher can be tempted to inappropriately ask sensitive questions and participants may reveal more information than they had foreseen (Richards & Schwartz, 2002). I paid attention to interviewees' emotional responses during the interview, but due to tremendous physical, social and mental strains faced by many of these patients it was difficult to define any clear limit of where to close the interview. Participants carried stories of social exclusion, abuse, loss of family members, impoverishment, anxiety, chronic hunger and hopelessness. All these factors were directly or indirectly linked with being ill with TB. Many cried during the interviews, but often they would express gratefulness that someone was listening. In one case a young participant became aggressive and threatening, accusing me of being callous listening to his suffering without helping him. At that time we had met three times, and he defined the

relationship we had as a relationship between *humans*, not as a relationship between a researcher and a participant. Even if this was the only time I was confronted about such an issue, I constantly felt a conflict between preserving a neutral role as a researcher, or taking on an advocate role as well as preserving my role as a fellow human being.

The analysis of qualitative data is influenced by theoretical frameworks, previous studies, personal characteristics, and preconceptions introduced by the researcher(s). Qualitative research has an interpretive nature, and the presented findings will only be a version of the “truth”. Subsequently, the trustworthiness of the findings must be evaluated in relation to the care with which the data was handled (Richards & Schwartz, 2002). I believe we limited misrepresentation of the findings due the systematic, dynamic and negotiated approach we took to the emerging data. By interviewing half of the patients three times, and by conducting two focus groups at the end of the study, we managed to validate and explore further most of the important themes.

The inconvenience and opportunity costs involved in qualitative research can be underestimated (Richards & Schwartz, 2002). In this part of the study participants participated in interviews for 2-3 hours, many of them 3 times and some of them being severely ill. Based on advice from local researchers we decided to compensate for inconvenience and opportunity costs by giving each patient 20 birr (at that time equivalent with 2.3 US dollar) after the interview. The concrete sum was never mentioned in advance, but the consent form informed that any related costs for participating in the interviews (like transportation costs), would be compensated. I did not experience that this compensation influenced the recruitment or ongoing participation in the study. I cannot, however, exclude the possibility that it might have served as a minor incentive among the participants that were interviewed three times.

Ethical approval for the Norwegian part of the study was obtained from the Regional Committee for Medical Research Ethics, Region South, Norway (reference: S-07186a). Norwegian Social Science Data Services granted us permission to make a temporary register of participants of the study (reference: 16619/LT). All participants were informed about the purpose of the study, and that they could withdraw from the interview and the study at any time without giving a reason and without penalty to their treatment. Written consent was sought in all cases. De-identification and confidentiality were ensured by using numbers to describe and identify patients.

As described above, there is an inevitable power imbalance between health personnel and patients, and the use of health personnel to help recruit patients to research may cause patients to feel pressured to participate (Richards & Schwartz, 2002). We sought to prevent such pressure by instructing the TB coordinators and the nurses in a way that would ensure that patients did not feel pressured to participate. Potential participants were approached with written information about the study by a TB coordinator or a nurse. The written information was provided in Norwegian, English, Somali and Amharic. The study and its terms were explained, and if the patient agreed to participate s/he could decide between contacting the researcher by phone, or to allow the researcher to contact them by phone. During the phone call the aim of the study and its terms were repeated and the participant would confirm whether or not they wanted to participate. In the interview setting we went through the consent form, repeated all the information about the study, and also emphasized that the participant could withdraw from the interview without any repercussions. As in the study in Ethiopia, we considered the consent as an ongoing process instead of a one-off event (Richards & Schwartz, 2002). At the end of the interview the participants were asked if the researcher could make contact to clarify issues, or for a second interview.

As described previously, the interpretive nature of qualitative research implies that the findings that are presented only represent a version of the “truth”. Thus, the trustworthiness of the findings must be evaluated in relation to the care with which the data was handled (Richards & Schwartz, 2002). Many of the participants’ had limited language skills in both Norwegian and English. Some of these patients were offered an interpreter, but refused due to many different and personal reasons. To avoid misrepresentation of the findings due to language barriers or general misunderstandings we decided to interview patients that had given unclear, ambiguous or incomplete answers twice. By interviewing these patients a second time we managed to clarify and validate the findings from previous interviews. Misrepresentation was also limited by interviewing health personnel about many of the same issues.

There are less than 300 cases of TB each year in Norway. Therefore, there is a clear risk of identification of the participants. It is not always easy to foresee which data may lead to identification (Richards & Schwartz, 2002), but we have intentionally used as few identifiable factors as possible when presenting cases and illustrating quotes.

4. Summary of results

4.1 Paper I

Sagbakken, M., Frich, J.C., Bjune, GA.

Barriers and enablers in the management of tuberculosis treatment in Addis Ababa, Ethiopia: a qualitative study.

BMC Public Health, 2008; 8: 11.

The aim of this paper is to explore enablers and barriers in the management of TB treatment during the first five months of treatment in Addis Ababa, Ethiopia.

We found that daily treatment was time-consuming and physically demanding, and rigid routines at health clinics reinforced many of the emerging problems. Patients with limited access to financial or practical help from relatives or friends experienced that the total costs of attending treatment exceeded their available resources. One group of patients still managed to continue treatment, mainly because relatives or community members provided food, encouragement and sometimes money for transportation. Lack of income over time, combined with daily accumulating costs and other struggles, made patients vulnerable to interruption during the later stages of treatment. Patients who were poor due to illness or slow progression, and who did not manage to restore their health and social status, were particularly vulnerable. Such patients lost access to essential financial and practical support over time, often because relatives and friends were financially and socially exhausted by supporting them.

We conclude that patients' ability to manage TB treatment is the product of dynamic processes, in which social and economic costs and other burdens change and interplay over time. Interventions to facilitate adherence to TB treatment need to address both time-specific and local factors.

4.2 Paper II

Sagbakken, M., Frich, J.C., Bjune, GA.

Perception and management of tuberculosis symptoms in Addis Ababa, Ethiopia.

Qual Health Res, 2008; 18: 1356-66.

The aim of this paper was to explore how symptoms of TB are perceived and managed from the onset of symptoms and during the course of treatment, in Addis Ababa, Ethiopia.

We found that patient's perceptions and self-treatment of early symptoms could cause diagnostic delay. Stigma associated with TB and public health services made many patients approach private clinics, causing further delay. Both private and public clinics often labeled and managed symptoms according to lay explanatory models. Lack of adequate knowledge concerning TB's etiology and cure caused patients to continue relating to symptoms by reference to their own understanding. This impacted patients' ability to manage TB and its treatment.

We conclude that addressing diagnostic delay will require simultaneous efforts to be directed at patients' communities and the health sector. Campaigns to destigmatize public TB services and make them more user-friendly are other important efforts. Reducing diagnostic delay could reduce some of the physical, psychological, social and financial burdens patients face during the long treatment regimen.

4.3 Paper III

Sagbakken, M., Bjune, G.A., Frich, J.C.

Experiences of being diagnosed with tuberculosis among immigrants in Norway – Factors associated with diagnostic delay: A qualitative study.

Scand J Public Health, 2010 (E-published ahead of print),

doi: 10.1177/1403494809357101

The aim of this paper was to explore experiences of being diagnosed with tuberculosis among immigrants in Norway, with a view to factors associated with diagnostic delay.

We found that one third of the participants reported less than two months from onset of symptoms to treatment initiation. The factors associated with little delay included a medical history that gave suspicion of TB, presenting with typical TB symptoms, or being screened for TB at arrival. Two thirds of the participants told about extensive diagnostic processes. Factors that could delay a patient's first initiative to seek help were persistent cough not accompanied by symptoms such as weight loss and weakness; mild, diffuse, atypical and/or intermittent symptoms; and a sense of not being a likely victim of TB. Participants experienced that the diagnostic process in the health services could endure for months, even years. The diagnosis could be difficult to confirm, but health professionals appeared to have difficulties associating their symptoms with TB.

We conclude that public health efforts to increase awareness about how TB is transmitted, its diversity in manifestations, and that TB can progress from latent to active disease, may decrease patient delay. An increased awareness among health professionals about typical and atypical symptoms of TB, aspects of the patient's history, and being aware and sensitive to patients' own interpretation of symptoms may reduce diagnostic delay in the health services.

4.4 Paper IV

Sagbakken, M., Bjune, G.A., Frich, J.C.

Patients' and health professionals' views and experiences with tuberculosis treatment in Norway.

(submitted manuscript).

The aim of this paper is to explore patients' and health professionals' views and experiences regarding the practice of directly observed treatment (DOT) in Norway.

We found that one group of patients experienced DOT as rigid and inflexible and felt that they had no power to influence their own situation. Those who had jobs or that attended school experienced that this lack of flexibility and unpredictability in how the treatment was organized had high social costs. Men in particular described DOT as humiliating and discriminating, while some of the women saw DOT as an expression of care and thorough follow-up. Those with positive experiences emphasized continuity among the health workers and the possibility to negotiate flexible treatment arrangements. We found that health professionals had divergent views about DOT. While one group argued that all patients should be treated equally and follow the rule of DOT throughout treatment, another group argued that DOT interfered too much in people's lives, and that one should aim for an individualized and flexible approach.

We conclude that in order to avoid disempowering and humiliating practices, care and treatment of TB patients should be organized in ways that create structures and decision-making processes that allow fully informed patients to express their views and negotiate their needs throughout treatment. To enforce profound changes, preservation of patient autonomy, empowerment and dignity must be part of the knowledge practice upon which DOT is based.

5. Discussion

5.1 Methodological considerations

5.1.1 Reflexivity

I started out with a general interest in exploring the social and cultural dimensions of a disease like TB through qualitative methodology. By engaging in the field I developed an interest in exploring how patients with TB perceive and manage symptoms and treatment of TB. I also developed an interest in exploring health personnel's views and experiences with TB and the related treatment. I chose to focus on how patients and health personnel interpret and manage symptoms in a low-endemic and a high-endemic context (paper II and III). I also chose to focus on how patients and health personnel view and experience TB treatment in the same two parts of the world (paper I and IV). By comparing views and experiences in two such different contexts, I sought to identify similarities and differences within and beyond specific contexts – and come closer to an understanding of challenges related to manage TB.

During my first fieldwork, in Addis Ababa, I set out to explore factors associated with adherence to TB treatment. During the study I found that diagnostic delay, indirectly, was one of the main reasons why TB patients were not able to adhere to their treatment. By the time patients had reached the clinics that provided TB treatment, many were too ill to cope with the demands of daily clinic attendance. In order to understand the phenomenon of adherence, I therefore found it necessary to explore patients' perceptions and management of early symptoms. What surprised me in this stage of the research was that the organization of the treatment (DOT) seemed to serve as a reason why some patients interrupted treatment. When I set out to conduct the study, I perceived DOT(S) as a program that would facilitate adherence; few studies had at that time documented barriers experienced by patients due to the implementation of DOT.

During the first interviews, religious and cultural interpretations of practicing sex (and related “sinful” behaviors) spontaneously emerged in participants' accounts, as relevant to adherence. This was another unexpected finding and in the beginning I did not understand the relevance enough to probe sufficiently. Due to thorough discussions of each interview, and vital inputs and initiatives provided by my research-assistant, we

included themes that otherwise could have been overlooked. Sexuality and sinful behavior turned out to be of overall importance to understand the phenomenon of adherence in this particular context.

In general, what I expected to be one of the main challenges in the study, the use of an interpreter, turned out to be one of the main assets. By continuously using the interpreter to broaden my understanding of the local culture, he served as a key informant. Through the eyes of the interpreter I was able to identify themes relevant in this particular culture and contextualize subsequent findings. Through my own observations I was able to question the unspoken; knowledge, values and norms taken for granted within the same culture. Through continuous discussions all the findings became a product of a thorough, transparent and negotiated understanding of what two people with different frames of references had seen and heard. Early in the research process I acknowledged that both the interpreter and I were co-producers of given accounts, and instead of working “through” him I decided to work “with” him (Wallin & Ahlström, 2006). Working “with” my interpreter also implied him playing an active role during the interviews by suggesting probes and initiating follow-up questions. In this way the interpreter and I became a close team which to an invaluable extent increased the trustworthiness of the data.

My preconceived ideas about potential findings from the Norwegian setting were few, since there was little literature on patients and health workers perceptions and management of TB in low-endemic contexts. Due to my findings from Ethiopia I had developed a more critical view about how DOT affected patients’ lives and their ability to manage their disease. However, most of the barriers that were experienced by patients in Ethiopia were poverty-related. I was therefore surprised to find that patients in Norway faced socio-economic consequences due to the organization of their TB treatment (DOT). What I did expect to find was that living in a society highly influenced by the bio-medical perspective would affect how people perceived and acted upon their symptoms. As suspected, people’s interpretations of symptoms had changed due to the new circumstances, but I was surprised to find that so few related to the lay categories that were used to describe symptoms of TB by patients in Ethiopia. However, when prompted, patients seemed shy to talk about interpretations other than the biomedical of TB. Sometimes I had the feeling that they did relate to other explanatory models, but due to the common use and acceptance of biomedical perspectives in Norway, patients were

reluctant to bring these ideas and concepts forward. Another possible interpretation, as suggested by my findings, is that a relatively consistent use of bacteria as part of the health workers' way of explaining TB, may have facilitated an another understanding and subsequent stronger adherence to the bio-medical perspective.

Religion (sinful activities) and its potential relation to healing was another theme that seldom emerged spontaneously among the Norwegian participants. There could be different reasons for this, but among the Muslim participants, sin and disease did not seem to have the same strong correlation as among Christian participants in Ethiopia, nor among some of the Christian participants in Norway. Another possible cause of the absence of lay, non-biomedical explanatory models is that patients in Ethiopia experienced much insecurity related to the etiology of the disease, and poor progress without adequate explanations seemed to facilitate a parallel use of different explanatory models – both among patients and health workers. Yet another possibility is that a large group of the participants in Ethiopia were interviewed three times, encouraging a level of trust and intimacy that I might not have managed to establish in one, or two, interviews with the participants in Norway.

Though I managed to talk with the participants in either Norwegian or English, without the potential disturbance of an interpreter, I found that working alone with the data caused a greater sense of insecurity. I missed the dynamic of having a partner to discuss each interview with; someone that could challenge my preliminary interpretations and vice versa. Some of the participants spoke limited Norwegian and English, but for different reasons they did not want to use an interpreter. Subsequently, the content of statements could sometimes be unclear or ambiguous. I sought to avoid such unclearities by transcribing the interviews immediately afterwards. Sometimes I called patients for clarifications, and eight of the patients were interviewed twice. In the process of analyzing the material, about half of the transcripts were read independently by me and my main supervisor, compensating to some extent for not having an assistant to discuss alternative interpretations with.

I was influenced by different theories, which may have inspired a broad approach to the questions this study seeks to explore. A debate taking place while being in the planning stage of the first part of the study revealed disagreement on the value of exploring culturally specific meanings and norms to understand a phenomenon such as adherence (Barnhoorn & van der Gest, 1997; Farmer, 1997). Farmer in particular argued

that “cultural variables” were overemphasized, and that the main answers in explaining adherence behavior were to be found by focusing on structural barriers. This debate inspired me to integrate different views in relation to the assumed importance and validity of which questions were to be asked. I believe that my findings have managed to illustrate that to understand how people perceive and manage TB these viewpoints are (to some extent) supplementary.

5.1.2 Trustworthiness and internal validity

In qualitative research, validity is related to the degree to which a method explores what it is intended to explore, and to what extent our data actually represent the phenomenon of interest (Kvale, 1996, p. 238). Kvale suggests that “to validate is to question” and recommends that critical questions are asked in all stages of the research process. By leaving these questions open to insight the reader may, to a further extent, be able to judge whether the study is internally valid. In this thesis, the methods chapter has met some of these requirements, but some additional points will be included and elaborated on here.

Participants in the Ethiopian part of the study (paper I & II) were recruited from three different clinics with similar DOT practices. The three research sites were considered to be “typical” DOT clinics and represented diversity being located in different areas of the city. We recruited 10 newly diagnosed TB patients on the basis of a purposeful sampling strategy, and 11 TB patients, whom had interrupted treatment. Patients who attended treatment and patients who had interrupted treatment were interviewed about the same themes, and part of the validation process involved identifying intersects between findings in the different groups. We supplemented the data further by including patients on re-treatment, relatives of patients, and health personnel. Observing communication and interaction patterns between health workers and patients in the clinics provided additional insight. At the end of the study focus group discussions were conducted to explore and validate previous findings. The findings are characterized by similarities within and between the different groups of participants. I believe that the trustworthiness of the study and the internal validity of the findings are strengthened by the extensive triangulation within the study.

There are no indications that there has been a selection of particularly economically poor participants to the study. The main findings in the study are poverty-related, but we most likely did not interview the poorest segment of the population. According to the local health personnel and the research assistant, the socio-demographic profile of the participants indicated that many were representing the lower middleclass. We saw indications of this during the study as many of the poorest residents did not manage to access the health services and interrupted treatment at an early stage due to the demand of daily clinic attendance. During the process of tracing those whom had interrupted treatment many had died or disappeared, several of them leaving to rural areas to secure food through relatives.

There may have been a selection of individuals that were in favor of biomedical treatment, and recruiting participants from alternative institutions might have provided a broader picture of how people perceive and act upon symptoms and treatment of TB. Almost all of the participants in the study adhered to the biomedical perspective, in the sense that they believed that TB medication was important to achieve a cure. However, there were many examples of change- or parallel use of different medical systems.

I used different strategies to ensure that I explored what I intended to explore, and that the data represented issues relevant to the questions posed in the study. The broad themes that were included in the interview guide were included on the basis of a thorough literature review and on several sources of theoretical inspiration. Acknowledging the complexity and dynamics of the subjects of concern I wanted to ensure that participants were exposed to the main themes that the literature had seemed to pinpoint as being relevant to the understanding of adherence. The study was therefore partly deductive, in the sense that important broad themes were pre-selected for inquiry. On the other hand, the reason why all these broad themes were included was to avoid limiting the focus to either e.g. “health-beliefs” or “structural barriers” and their separate influence on the management of TB. By including all (seemingly) major themes I wanted to allow the participants themselves to define the importance of different factors. I also wanted to ensure an understanding of how important variables could be interrelated and subsequently provide a “thick description” on the subject of concern. To ensure a representation of lay experiences and theories I gradually included and explored themes as they were emerging from the field. By using open-ended questions and to a

certain extent a narrative approach, I sought to enable participants to identify and emphasize what they considered important.

As described in the method chapter, the number of health personnel interviewed in this part of the study is limited and inclusion of more health personnel would have ensured a more valid representation of this group's views and experiences.

Another issue regarding the trustworthiness of the data, of particular concern working with an interpreter, is critical language awareness as emphasized by Willig (2008, p.11). "Language does not simply mirror reality": Words can carry accumulated and particular cultural, social, and political meanings. The same phenomenon can be described in different ways and give rise to different understandings. Working with an interpreter I was particularly concerned about establishing a shared understanding of the content in the research project. We thoroughly discussed the research protocol and the aim of the study, in which the assistant contributed valuable inputs. The interview guide was translated back and forth several times, the last version being a negotiated product between me and the research assistant. During this process we discussed and clarified each others interpretation of important words and concepts to be used in the study. During the interviews and in the process of listening to the taped interviews, I emphasized that meaning should have priority over form. This implied that instead of focusing on word-by-word translation I encouraged the interpreter to translate in a way that gave the right meaning to the statement. Translating the form and meaning of a statement in one language into a corresponding form of another language may actually change the meaning, and thus reduce the trustworthiness of the data (Wallin & Ahlström, 2006). The transcriptions were conducted in a way that was as close to a verbatim translation as possible, still taking into account the preservation of meaning. The assistant included pauses, emphases in intonation, emotional expressions like crying or laughter, observations regarding body-language, and the use of irony by including "ironic" in brackets. In agreement with me (after listening to the taped interviews), parts of the interview that had little relevant information were condensed and summarized.

In the Norwegian part of the study (paper III & IV), a purposeful sample of study participants were recruited through primary health care services and six main hospitals in Oslo/Akershus; the region where more than one-third of the TB cases in Norway

occurred in the study period. 22 TB patients who originated from either Somalia or Ethiopia were recruited for the study. Data from the Norwegian Surveillance System for Communicable Diseases (MSIS) show that the number of reported TB cases in 2005 and 2006 were highest among people who originated from Somalia and Ethiopia (not including Norwegian-born) (Winje et al., 2006b; Winje et al., 2007). We thought the experiences of these two groups would be of particular interest to health workers and policymakers. We also had an interest to include participants originating from the same geographical area as the previous study, allowing some type of comparison, for example in relation to interpretation of early symptoms. Health personnel in relevant positions in a variety of districts/hospitals were contacted by phone for a potential interview. Some were recruited by snowball sampling, as participants were asked to identify potential participants who could provide relevant information. The final sample consisted of 20 health personnel; of whom eight were doctors, five were TB coordinators, two were community nurses, and five were nurses from home-based services.

There are no indications that there has been a selection of patients with certain types of experiences in the study. Most of the patients were recruited through TB coordinators, and even though some of the TB coordinators seemed eager to identify participants that were satisfied with how the treatment was organized, other TB coordinators emphasized the importance of trying to identify patients that they thought had different experiences. During the data collection period, a total of 10 persons originating from Ethiopia and 30 persons originating from Somalia were diagnosed with TB in Oslo/Akershus. I ended up interviewing a large proportion of the actual cases: Seven out of 10 existing patients from Ethiopia, and 15 out of 30 existing patients from Somalia. During the recruitment of health personnel I found that there was a variety of views regarding the practice of TB treatment (DOT). Through snowball sampling I was therefore able to recruit health workers that I was told had different/contrary opinions or practices.

I used various strategies to ensure that I explored what I intended to explore, and that the data represented issues relevant to the questions posed in the study. The same approach as described in the first part of the study was used to ensure internal validity in the Norwegian fieldwork. On the basis of a literature review, experiences from the previous study from Ethiopia, and several sources of theoretical inspiration, I decided to base the questions on selected broad themes. This time I was more explicit in seeking to

explore experiences related to the diagnostic process. To ensure representation of lay experiences and theories I gradually included and explored themes as they were emerging from the field. By using open-ended questions, and to a larger extent than in the first part of the study, using a narrative approach, I sought to enable participants to identify and emphasize what they saw as important. After some interviews the semi-structured interview-guide was replaced with a thematic check list, and the participants, to a large extent, set the agenda.

Some patients had limited language skills in Norwegian or English, which may have caused misunderstandings during interviews. However, I sought to modify this weakness by immediate transcription and clarifications through phone-calls or a second interview with some of the participants. The transcriptions were verbatim, but I included comments in brackets where I suggested explanations to statements that seemed unclear. At the end of each transcription I made a summary of the main content, made comments related to the atmosphere during the interview, and systematically wrote down issues which needed to be clarified. Further comments were added after I had clarified issues through phone calls with some of the participants. Pauses, emphases in intonation, emotional expressions, and notes regarding observation of body language were included in the transcriptions.

A weakness of this part of the study is that all of the data from patients is based on interviews and retrospective accounts. We have no data on what actually took place in the medical encounters that our participants refer to. Participants may have recall bias regarding type, severity, and onset of symptoms, or may have moral or psychological reasons for attributing delay or other negative experiences solely to the health service system. One may therefore question the validity of participant's accounts. Also, the health personnel may have had moral or psychological reasons for claiming certain views. The methodology would have been strengthened if the context had allowed for the use of observation. However, the strength of the study lies in the homogeneity and coherence in the answers within and between different groups of patients and health personnel. We found that patients' accounts to a large extent were confirmed by health personnel, and there is nothing in the data suggesting that we should distrust their accounts. Data about how participants experience the health services should be considered as

valid in their own terms, as patients' experiences are important clinical outcome measures (Annandale & Hunt, 1998).

5.1.3 External validity – transferability

Transferability means that findings, interpretations and concepts from one study may be transferred to another context and be valid in that context. This also implies that the findings must be considered interesting and relevant to researchers, policymakers or health workers in other settings. Kvale states that “pragmatic validation rests on observations and interpretations, with a commitment to act on the interpretations” (Kvale 1996, p. 248). The pragmatic validity will be especially important in research with an indirect motive of change: Without applicability or practical relevance, the knowledge obtained will not be of much use. In our search to understand how patients with TB perceive and manage their disease we have conducted two different studies. The first study context represents a high-endemic, low-income setting while the second study context represents a low-endemic, high-income setting. We have decided to focus on how patients interpret and act upon symptoms, in interaction with health personnel, in two different parts of the world (paper II & III). We have also chosen to focus on how patients and health personnel perceive and experience TB treatment, organized as DOT, in these same two parts of the world (paper I & IV). In each of the two studies, measures have been taken to ensure that the sample would provide data that would be of relevance, according to the aim of the study. This has been attended to by the described procedure for purposeful sampling, and by including the perspectives of both patients and health personnel. We did not aim for a representative sample in an epidemiological sense. However, we have observed that the sample does not deviate much from the population group as a whole with regards to certain characteristics. Data from SSB (2010c) show that few individuals from Somalia are integrated in the labor market. In 2008, only 45 % of Somali men were employed and only 25 % of the women. Many Somali women live alone with children, and struggle with their finances. People from Somalia represent the group (together with people from Iraq) that most often only hold temporary employment positions (SSB, 2010a). People from Ethiopia are more integrated in the labor market, and the differences between sexes are less. In 2005, 54 % of all first generation Ethiopian immigrants were employed (SSB, 2007). Compared to the overall population, Ethiopians are overrepresented in the hotel- and restaurant business (SSB, 2007), which often implies shift work and irregular working conditions.

The sites selected for recruitment of participants have sought to ensure “representativeness” in the sense that we have recruited participants within a geographical area with a (relatively) high number of TB cases, and from a variety of clinics/sites. We should, however, emphasize that the sample of patients from Norway was restricted to people who originated from Somalia and Ethiopia. These two groups represent heterogeneous cultures, and the findings may not be representative of all immigrant TB patients in Norway.

We have employed qualitative methods to explore the research questions in this study. Kvale’s definition of validity includes a focus on the pragmatic value of research, or in other words whether studies that are being conducted are reflecting variables of interest (Kvale, 1996). This relates to transferability in the sense that the meeting between the study and the research community, policymakers or health workers will be a test of whether the study reflects methods and findings of interest. The study from Ethiopia has received a lot of interest and the preliminary findings have been presented at three international conferences and at a variety of meetings with relevant stakeholders. The preliminary findings from the study in Norway have been presented at two international conferences, and at a yearly gathering of TB coordinators in Norway. During this process I have received important support, comments and reflections, which have greatly encouraged me to continue in the publishing process.

The insight produced through each part of the study and the insight provided from the study as a whole will possibly represent two different dimensions of interest. By exploring views and experiences in a high-endemic, low-income setting versus a low-endemic, high-income setting, we may identify factors that serve as common challenges and potential solutions. Examples of findings that might be transferable across different contexts are found in papers II and III. These papers explore how people living with TB in two different parts of the world perceive and manage their symptoms. Our findings show that patients, independent of context, perceive TB as a serious lung disease associated with poverty. We found that participants in both contexts associated TB with a persistent cough, but due to its perceived severity people would (often) not suspect TB in the absence of symptoms such as weight loss and weakness. Even though these interpretations were similar, interpretations and management of symptoms

may be modified or changed when one moves from a country where the prevalence of TB is high to a country with a low prevalence. Paper III shows that patients may perceive themselves as unlikely victims of TB while living in affluent parts of the world. Persistent cough may be interpreted as a common cold, and the meeting with a health system lacking in awareness of TB may strengthen such an interpretation. Our findings related to patients' and health workers' experiences of TB treatment (DOT) in papers I & IV show that patients in a low-endemic setting may experience barriers related to the organization of treatment similar to those described in a high-endemic setting. Considering the disparity in available resources, this is a surprising finding. However, as illustrated in our study, the groups that have the most difficulties adapting to the DOT system share some characteristics. For example, paper IV illustrates how patients in Norway, who did not have permanent jobs, were particularly vulnerable. This is in line with the findings from Ethiopia. These findings should encourage the research community to conduct research in other low-endemic settings. Further, it should encourage policymakers to reconsider or modify present methods of ensuring treatment completion and cure for TB. However, the reception among policymakers – and the subsequent pragmatic value of these findings – still remains to be seen.

5.2 Interpretation and management of symptoms – diagnostic delay

5.2.1 Addis Ababa, Ethiopia

In Ethiopia we found that early symptoms of TB were interpreted and acted upon according to local explanatory models. Often a cough was not recognized as possible TB unless accompanied by serious symptoms like weight loss and hemoptysis, similar to findings from other settings (Nair, George, & Chacko, 1997; Demissie et al., 2002; Storla et al., 2008). Early symptoms of TB were categorized as a culturally explained disease (*bird*) and often attended to by self-treatment inspired by the popular or the folk sector of the health care system (Kleinman, 1980). Even if most people described self-treatment of early symptoms as a response to a culturally specific interpretation, implicit economical barriers are most likely part of the rationale in which people make their choices. People know that going to a health centre will cost money, even the public centers. There will be expenses related to transport, diagnostic procedures, as well as an incurred

loss of income and opportunity costs caused by time used queuing up in public clinics. In line with Becker and Maiman (1975), and Becker (1990), health behaviors may be shaped by factors such as availability and accessibility of services as well as by the perceived severity of the disease. Stated differently, strategies such as self-treatment may (partly) be a function of structural barriers in the society at large.

In paper II, we explore how stigma associated with TB and public health services made many patients, despite the costs, use private health services. Public clinics were stigmatized because they were considered to be for the poorest people, and patients were reluctant to expose themselves lining up in queues at such clinics. According to Goffman, stigma represents an attribute that is perceived as deeply discrediting in a social relationship or context (Goffman, 1968, p.13). Stigma that is directly associated with living in poverty has been found to negatively influence health through psychological distress. Shame, inferiority, and disrespect from others are sources of stress and anxiety, which can reinforce the stress associated by being infected by a disease in the context of inadequate economic resources (Reutter et al., 2009). In our study (paper II) we found that TB carried several stigmas related to the etiology of TB. Circumstantial causes such as poverty and sinful behaviour; including the close association with HIV/AIDS, made people reluctant to reveal which disease they were suffering from. This was illustrated through patients' continued use of the illness taxonomy *bird* to explain their symptoms, even after being diagnosed with TB. To avoid judgemental talk and exclusion by community members, patients protected themselves by explaining their symptoms using the more harmless, non-stigmatized illness taxonomy *bird*. The extensive use of *bird* can therefore be seen as "impression management" (Goffman, 1968), or as a strategy intended to enhance acceptance and avoid social exclusion. A study in Somalia found that pressure due to stigmatisation could lead to two types of concealment; hiding of TB and/or the denial of the symptoms and disease (Serkkola, 1998). If hiding or denial of symptoms is a common practice, many people may never reach government health services because of psychosocial barriers. Stigma has, in different ways and in several settings, been associated with diagnostic delay (WHO, 2006; Storla et al., 2008).

The use of private clinics has another dimension, not explicitly elaborated on in paper II. Some participants shared that one of the reasons they preferred private clinics was that they could not afford to lose a full day's work, or even risk losing their jobs, having to queue up in a government clinic. An early study from Addis Ababa (Teklu, 1984) supports this claim by reporting that one reason for treatment interruptions was that employers or private persons refused to give permission for their employees or domestic servants to go to the TB center to collect their drugs. A synergistic effect of stigma, lack of permanent employment, and lack of rights as an employee, may lead to a long delay period because people, due to many reasons, spend time saving money to go to a private clinic.

The beliefs and behaviors that constitute different activities in the health care system are heavily influenced by social institutions, social roles, interpersonal relationships, interaction settings, economic and political constraints, and a number of other factors (Kleinman, 1980). We found that both private and public clinics in the professional part of the health sector in Ethiopia labeled and managed symptoms according to lay explanatory models. In paper II, we describe the repeated visits made by patients at the same level of health care without receiving a proper diagnosis, particularly in the private sector. Diagnostic delay, due to several visits at the same level in the health care system, has been described in several other settings (Storla et al., 2008). In paper II, we suggest that the practice of repeated consultations, including repeated courses of non-specific antibiotics, may be related to financial incentives among private practitioners. However, there were many examples of health personnel who understood TB within a traditional framework. Independent of cause, classifying and managing symptoms by reference to lay explanatory models made this knowledge part of the "clinical reality" (Kleinman, 1980), and an important arena for disseminating awareness of how to interpret and manage TB according to the perspective on which the treatment is based (biomedical) is lost. A study from an English suburban community has shown how the biomedical model can be adapted so that it "makes sense" in terms of the folk models of illness (Helman, 1978). Regardless of motivation, it can be argued that in Addis Ababa such overlapping is inexpedient, because it delays diagnosis and affects people's perceptions and management of symptoms throughout treatment. The public health implications are great, as delay in diagnosis increases the period of infectivity, and as demonstrated in this context, seriously affects management of

treatment and the severity of the disease. Since health personnel relate to both indigenous and bio-medical knowledge, there should be potential for finding rational ways of communicating with patients; in which symptom interpretation and subsequent treatment makes sense.

5.2.2 Oslo/Akershus, Norway

In the Norwegian study, we found that persistent cough not accompanied by symptoms such as weight loss and weakness could be interpreted as inconsistent with TB. Cough and fever were often interpreted as harmless symptoms, and were treated in accordance with a common cold. Paper III shows that the interpretation and management of symptoms can be modified or changed when one moves from a country where the prevalence of TB is high to a country where the prevalence is low. Some patients told that persistent cough would have raised a suspicion of TB in their home countries, but that the new context, Norway, had influenced their interpretation of symptoms. Causal associations between poverty/poor nutrition and susceptibility to TB; and a sense of not being a likely victim of the disease, could delay the first initiative to seek help. In addition, most patients were not aware of the possibility that they could carry a latent infection, which increased the sense of not being vulnerable.

Stigma was raised as a cause of delay by only one patient in the Norwegian material. In the meeting with his doctor, this patient was deliberately hiding symptoms associated with TB, because he feared the social consequences of receiving such as diagnosis. One of the reasons why stigma seems to play a minor role in diagnostic delay in Norway may be that the public sector is the main source of health funding (ca 84 per cent) (SSB, 2006). Subsequently patients may utilize public services without the risk of being stigmatized. In addition, less awareness about TB in the society reduces the risk of people associating your symptoms with TB.

Patients' health seeking behavior must also be understood in the light of structural barriers or enablers within the society at large. Even though TB drugs are free in countries that have implemented DOTS, the costs that patients bare before treatment are, as discussed earlier, of major importance. Seeking a diagnosis in Norway implies costs, but living in a welfare state most likely prevents that people have to balance the costs of initiating medical help with costs related to daily needs. Health services in Norway are made accessible by a share-cost system which implies that patients only pay a share of the costs when they receive treatment by a general practitioner, by a

psychologist, a specialist outside of a hospital, for prescriptions of important drugs, and for transportation expenses in connection with examination or treatment. A cost-share ceiling (NOK 1840 in 2010) ensures that people that have needs that require frequent health care visits, do not have to worry about costs beyond the defined ceiling (for the rest of the calendar year) (Norwegian Ministry of Labour, 2010). In line with Becker and Maiman (1975), and Becker (1990), we may say that even though the perceived vulnerability to TB is lower among the participants in Norway, the perceived costs (financial, psycho-social) of initiation of health care is also lower; which may serve as a cue to action.

The beliefs and behaviors that constitute different activities in the health care system are heavily influenced by many other factors, such as the interaction with health personnel (Kleinman, 1980). We found that health personnel in Norway lacked awareness of both atypical and typical symptoms of TB, and the level of suspicion seemed to be determined by the epidemiological situation in Norway, and not by the epidemiological situation in the patients' country of origin. Many of the patients that suspected TB experienced that they were not taken seriously and consulted with several doctors during their search for a diagnosis. As a result, the diagnostic process could endure for months, even years, after the first meeting with the health services. These findings are supported by a previous study from Norway, based on data from the National TB Registry, clinical case notes from hospitals, and referral notes from primary health care providers (Farah et al., 2006). This study found a median total delay of 63 days from the onset of symptoms to the initiation of TB treatment. The delay was primarily attributed to doctors not initiating TB specific examinations despite symptoms suggesting TB. The authors of this study emphasize the need for awareness of TB in the general population and among health personnel in order to reduce diagnostic delay. A recent publication on TB screening and follow-up of asylum seekers in Norway concluded that the coverage of screening was satisfactory, but fewer suspect cases than one would expect were followed up in the community and referred to a specialist. In line with Farah et al. (2006) the author points to a limited focus on TB among health workers and in the society at large (Harstad et al., 2009).

5.3 A cross-cultural perspective on diagnostic delay

Our study shows that patients in both Ethiopia and Norway perceived TB as a severe lung disease. Awareness of early symptoms (e.g. persistent cough) seems to be low in

both contexts. Or rather, even though people associate TB with persistent cough, cough alone is seldom enough to make people act, based on a suspicion of TB. Assessing the findings in both studies, what seems to complete lay people's symptomatic picture of TB are symptoms from the lungs (cough, hemoptysis, dyspnoea) combined with symptoms suggesting lack of food/poverty (weight loss) and symptoms suggesting severity (weakness, tiredness, fever, weight loss). Even though most people are aware of some sort of interpersonal transmission, TB is, in both contexts, first of all strongly associated with poverty, and subsequently with a disease that affects certain countries or certain layers of a population. Thus, people have more knowledge about the sociological causes of the disease than the microbiological cause. In the Norwegian study we found that many patients had learned about the microbiological perspective through doctors. Patients had then integrated the bacteria into already existing explanatory models. The bacteria were perceived as the agent that caused infection, and that carried the disease between people. However, most participants still saw TB as "circumstantial" in the way that living in poverty, exposure to certain elements (cold, wind, dust), or conducting sinful behavior were also seen as underlying causes. The absence of such circumstances (poverty in particular) made it difficult to understand why they had become vulnerable to the disease. In other words, even if patients internalize elements of bio-medical medicine it does not necessarily mean that the elements are emphasized or interpreted in the same way as within bio-medical medicine.

Paper II suggests that lay categorizations of early TB symptoms converge with diagnostic practices in parts of the professional sector in Ethiopia. Due to such practices the diagnostic process could endure for many months after patients' first contact with the health services. Similarly, in paper III, we show that patients' interpretations of symptoms often are confirmed in the meeting with health personnel in Norway. As in Ethiopia, the consequences are that the diagnostic process is prolonged. In paper I, we suggest that patients' long diagnostic trajectory, receiving repeated treatment with non-specific antibiotics in different parts of the health care system, could be profit motivated. The epidemiological situation in Ethiopia should imply high awareness of TB, but as illustrated in the material, health personnel also lack awareness or misinterpret early symptoms of TB. In Norway, a quantitative study from Oslo/Akershus found diagnostic practices somehow similar to those in Ethiopia. The study found that the main reason for the long total delay was that doctors did not initiate TB specific tests in patients with

symptoms of TB before treatment with antibiotics had failed (Farah et al., 2006). We found that there were no examples of patients draining their resources in the private sector, but several patients changed doctors and received subsequent treatments with antibiotic. One reason for delaying specific diagnostic tests may be the low prevalence of TB in Norway, and one may consider TB to be an unlikely diagnosis.

In line with Becker, we may conclude that TB is perceived as severe in both contexts, while the perceived vulnerability differs greatly. In Norway, the effect of perceived low vulnerability is somehow balanced by few socio-economic barriers, which may represent a trigger to action at an earlier stage. In Ethiopia (even though awareness of early symptoms is low), the epidemiological situation implies a perception of vulnerability that is higher. However, social and financial barriers in the society at large seem to outweigh the potential that lies in such awareness. Health care system delay is, for different reasons, high in both contexts, although mostly related to either lack of awareness of TB; of typical or atypical symptoms; and poor diagnostic routines or lack of diagnostic tools.

5.4 The burden of treatment and its consequences

5.4.1 Addis Ababa, Ethiopia

In the study from Ethiopia we found that daily clinic-attendance is time-consuming and physically demanding, and that the rigid routines at the health clinics reinforce many of the emerging problems. Our findings are in concordance with findings from other high-endemic settings (Munro et al., 2007a). In a country where people often do not possess the benefit of having a permanent job, or social security benefits when one gets ill, a serious illness like TB may carry consequences such as loss of work or the possibility to work as a day laborer. In paper I, we describe how a patient's loss of job and/or income occurs at a point in time where many have drained all their economic sources (diagnostic process), but where they need extra money to cover expenses related to daily clinic-attendance and procurement of protein-rich food. The emphasize on protein-rich food made patients feel powerless; knowing that certain type of food would make the TB treatment more efficient, and yet not being able to access even basic food items on a daily basis. Even though the need of protein-rich food was explained within a traditional framework, a good nutritional status and the value of protein-rich food in particular, are to some extent supported by the literature. Protein-energy malnutrition and micronutrient

deficiencies increase the risk of developing TB, and it has been found that malnourished TB patients have a delayed recovery as well as a higher mortality rate compared to well-nourished TB patients (Gupta, Gupta, Atreja, Verma, & Vishvkarma, 2009).

Our findings (paper I) suggest that patients who have fewer human or material resources available in their environments, such as the very poor, single mothers, and working immigrants from rural areas are the most vulnerable to treatment interruption. Such groups may interrupt already at early stages of treatment, and many within this category may never initiate treatment. The TB case detection rate in Ethiopia is very low with only a 28 % detection rate of new smear positive cases and a 40 % detection rate of all TB cases (WHO, 2009d). Heavy treatment related burdens, disseminated by TB patients to the community, may influence people's health seeking behavior, and as such influence the level of passive case detection. Another patient group that is particularly vulnerable to treatment interruption are those whom become impoverished due to illness or slow disease progression, and who do not manage to restore their health and social status. These patients end up in a vicious circle, where their physical condition contributes to income poverty; further dependency; emotional exhaustion; and sometimes loss of hope. In paper I we argue that a decision to interrupt treatment may be shaped by past struggles and accrued costs, which may seem emotionally, socially or financially unbearable at the moment the decision is taken (Christensen-Szalanski & Northcraft, 1985).

Paper I also demonstrates how structural barriers may be compensated for by social support mechanisms in the society. Lack of public social security systems pave the way for different types of reciprocal arrangements: To help a neighbour in crisis is to invest in your own social security. However, at the point someone's condition is interpreted as fatal, community members may reduce their support based on the fact that the diseased person will no longer be able to contribute within the reciprocal system. We may say that the community's response towards persons in severe and prolonged life crisis seem to move from a "generalised reciprocity" (sharing of resources without strict obligation to repay) towards a more "balanced" type of reciprocity (less moral, more economic way of sharing resources) (Seymour-Smith, 1986, p.241). A study from Somalia (Serkkola, 1988) concluded that a serious disease like TB changes the "normal social order". Attitudes and behavioural patterns were shaped on the basis of values and norms rationalizing both avoidance and support, and responsibility for a diseased person

was found not to correspond with the traditional loyalty founded on kin. According to Coleman (1997, p. 148), stigma may be used to justify exclusion based on fear of having to share material resources for prolonged periods of time. Thus, economic exclusion can be legitimized by viewing it as a consequence of a moral exclusion, since emotional and cognitive distancing is linked with other types of distancing (Reutter et al., 2009). In paper II we argue that the professional part of the health care system may counteract prolonged use of existing support mechanisms because stigmatizing notions about TB are brought back and confirmed within the social reality of lay people.

5.4.2 Oslo/Akershus, Norway

We found in the Norwegian study that a majority of patients experienced DOT as rigid and inflexible and felt that they had no power to influence their own situation (paper IV). Those who had jobs or that attended school experienced that this lack of flexibility and unpredictability in how the treatment was organized had high social costs. Those that did not have a permanent job were the most vulnerable (paper IV). Men in particular described DOT as humiliating and related this to the powerlessness they felt by having to accept a treatment that interfered with their social life and their working life. The information/practice of DOT was experienced as authoritarian and lacked transparency, in which made several of the participants view DOT as a treatment that were only practiced on immigrants from poor countries.

Only one patient in the material interrupted treatment, which may be due to the close monitoring of a relatively small patient group. Most patients had an address or a telephone number where they could be traced if they interrupted, making it difficult to “disappear” from the system. The only patient in the study who did interrupt treatment, claimed she was given up by health personnel due to the unpredictability she caused by her frequent change of address. Another explanation for why so few patients seem to interrupt their treatment may be that the Norwegian health personnel gave information that provided a more concise and logical explanation of the disease and its treatment. Patients explained how the information they received from Norwegian health personnel made them realize that TB was a “normal disease”; that it was not chronic; that it was treatable and that they would not die. The bacteria were perceived as an agent possible to fight; that carried less alternative explanations; and subsequently less stigma. Many patients felt they avoided “talk” and judgmental attitudes by avoiding the term

tuberculosis and instead telling people that they were suffering from an “infectious disease” or a “bacterial disease”. This “impression management” was often facilitated by the absence of the “classical” signs of TB (as pronounced weight loss and visible weakness); since few of the participants in this part of the study suffered from such symptoms.

Another important factor, not elaborated on in the papers from Norway (paper III & IV), is that patients tended to believe that the medicine they got in Norway was better than what they would receive in their home countries; strengthening the belief in the existing bio-medical treatment. While patients in Ethiopia seemed to stay in treatment because they feared the (insecure) consequences of interruption (dying), patients in Norway seemed motivated to stay on treatment because they knew they would survive. Since most patients felt confident that they were not going to die or be chronically ill, they did not depend on engaging in vulnerable reciprocal relationships to secure economic or other types of support from relatives and friends. Such confidence was, to a certain extent, supported by the fact that they were receiving treatment within the frames of a welfare state. Not having to expose ones vulnerability, nor depend on others, may have reduced felt as well enacted stigma. Thus, the social and financial burden of being ill appears to be far less in this context, which may serve as the main reason why people complete their treatment regimens.

5.4.3 Cross cultural perspectives – the burden of DOT

Findings related to patients’ and health workers’ experiences of TB treatment (DOT) in Norway and Ethiopia show that different contexts produce different types of experiences. However, there are similarities related to how the organization of treatment is experienced, and how DOT affects certain patient groups. In Ethiopia we found that those struggling the most to manage treatment were members of vulnerable or marginalized groups; the poor; the homeless; single mothers; those employed as day labourers; those working in the private sector; those lacking rights as an employee; those without social security rights; those having migrated to Addis to get a job or to get TB treatment; and those lacking a social support network.

Comparing the findings in Ethiopia with the findings in Norway we see parallels. One parallel is the rigidity in the system, and a lack of individual adjustments to the patients’ social and working life, which cause barriers that make it difficult to

simultaneously attend to demands related to treatment and demands related to other areas of life. Further, even though the extreme poverty related barriers in Addis Ababa are not comparable to the situation for TB patients living in Norway, there is still a tendency that the most vulnerable patients are those who have the most difficulty adapting to the DOT system. Paper IV shows that patients in Norway who did not have permanent jobs were particularly vulnerable. This is in line with the findings from Ethiopia. One group of participants in Norway had provisional engagements involving shift work or work agreements made on a day-to-day basis. These conditions caused a vulnerability that participants sought to compensate for by presenting themselves as reliable, flexible shift workers; qualities difficult to assert due to the DOT arrangement. Many of those that had been through long diagnostic processes had not been in a position where they could claim a sick leave, and due to illness they had gradually reduced their number of shifts. This led to an unfortunate economic position both before and during the treatment. Others described difficulties receiving money through the social services after they had been diagnosed; either because their work was not documented or because their previous income was based on work agreements made on a daily basis. There were cases where patients had their electricity and telephone closed due to inability to pay the bills. Many were troubled because they could no longer afford to send money to relatives in their home countries.

In a study from India, Singh et al. (2002) reported an algorithm that excluded mainly poor and disadvantaged patients. This algorithm was based on “suitability criteria’s” for DOT, while other groups were considered less suitable. The less suitable were socially marginalized groups such as the poor, those not having ration cards, members of the lower castes, alcoholics, and abandoned or widowed mothers. Other criteria making patients less suitable for DOT were a low level of integration in the city (such as patients that had recently moved to Delhi, patients staying in Delhi for a short time, or patients being recent migrants to Delhi with their families still living in the village), and patients who were daily wage earners, or a contract or factory worker with shift duties. It was also important to decide whether patients were difficult to reach or not; living in a house difficult to locate or in a house being far from the clinic. The migrants from rural areas (i.e. the poorest) were by health personnel described as those that could be ‘least trusted’ (Singh et al., 2002). The criteria made to disqualify patients in this study serve as a description of the groups that experienced the most problems

adapting to DOT in our study as well. These criteria acknowledge the fact that these particular groups most likely will struggle to adapt to DOT, and subsequently represent patients that might have a poor outcome. The study also serves as an illustration of how vulnerability and social inequality erroneously may end up being interpreted and treated as recalcitration.

Patients in both studies reported a series of humiliating experiences being treated by DOT (paper I & IV). However, even though the stories that were told by patients in Ethiopia mirrored humiliating experiences, humiliation seldom emerged as an explicit notion in the interviews conducted in Ethiopia. There could be different explanations for this, but Maslow's hierarchic theory of needs can represent a possible explanation. Maslow introduces a hierarchy of five levels of basic needs: Physiological needs (needs of oxygen, food, water etc), safety needs (needs for protection, feeling safe), social needs (needs of love, belongingness, friendship), needs for esteem (needs of self-respect, self-confidence, appreciation, social status, dignity), and needs for self-actualization (realization of personal abilities, aims). Beyond these needs, higher levels of needs exist, including spiritual needs and needs for understanding (Maslow, 1943). Even though Maslow's theories have been criticized of being linear (Neher, 1991), it is possible that individuals who manage their illness in the midst of poverty, hunger and hopelessness, are less receptive – or rather – may suppress needs related to self-esteem. Subsequently, patients who experience that their physiological and safety needs are covered may express social and psychological needs more explicitly. Another explanation may be that there are differences in the expectation of autonomy, and that DOT (to some extent) may be accepted in one context, while being experienced as humiliating in another context.

Let us return to the debate between Barnhoorn and Farmer (Barnhoorn & van der Gest, 1997; Farmer, 1997), about which factors are most relevant in understanding why patients may not complete treatment. The discussion centered on to what degree themes like health beliefs are important in understanding non-compliance to TB treatment. Farmer argued that these approaches are overemphasized and that studies fail to recognize the wider influences on patients' lives such as poverty, conflict, political instability, and racial and gender inequalities. This study shows that Farmers emphasis on structural barriers is of major importance in understanding the burden of illness and treatment. Structural barriers in the society at large can explain, or at least partially explain, why and how people interpret and manage their disease and the treatment in the

way they do. However, it is also important to understand the impact of local cultural interpretations and practices, in particular when such practices impact on TB patients' ability to manage treatment. An example of this is the importance of understanding the use of the illness taxonomy *bird*; a cultural conception used in both the folk, popular and the professional part of the health care system in Ethiopia. Even if *bird* cannot be directly related to treatment interruptions, it is a component that guides beliefs and activities among TB patients and health personnel; from symptom recognition and management, to diagnostic procedures; all activities of which indirectly affect treatment adherence. Yet again, the extensive use of the illness taxonomy *bird* can be understood as poor people's efforts of preventing further loss of social and economic power.

Assessing the health worker-patient relationship we might find a dimension that somehow corresponds with both Barnhoorn & van der Gest and Farmers' perspective. In a patients' search for diagnosis and treatment, they depend on health personnel's competence, but also on their ability and will to provide information that might empower patients to make informed decisions in their efforts to regain their health. Patients also need environments where they feel free to ask questions and gain the knowledge necessary to make such decisions. Homedes and Ugalde (1993) draw attention to the socio-economic, educational, cultural and linguistic differences between patients and health workers and how that complicates the health worker-patient relationship. In Costa Rica, they followed 404 consultations where 1023 medications were prescribed, and found that only 10 of those consulted asked for clarification about the prescription. Homedes and Ugalde claim that patients with low income or low education seldom ask for clarification or additional information, and even less frequently question their doctors' practices.

In the Ethiopian context we found that patients were not provided the information they needed to understand their symptoms and their treatment. Similarly, patients did not feel free to ask for clarification, or to question diagnostic procedures or treatment practices. A variety of causal attributions assigned by the individual or the health workers affected the patient's ability to access, obtain and maintain relevant treatment. In line with Barnhoorn & van der Gest, what finally killed the participant that interrupted treatment and went for "holy water" (paper II) was his confusion over the etiology, symptoms and prognosis of his disease; a confusion that was strengthened in the interaction with local health workers. A mixture of cultural and religious

interpretations served as a way of disciplining the patient group, so that they would stay focused and not become recalcitrant during treatment. By withholding and adjusting information a desired power imbalance was preserved, and patients remained dependent, vulnerable and powerless. According to Kleinman (1980, p.52) the power to legitimate certain interpretations as the “right” or only ‘clinical reality’ is not equally distributed. The professional sector is sovereign because social power, to a large extent, depends on institutionalization, and while the popular sector is diffused, the professional sector is largely institutionalized. Subsequently, the power behind the explanatory models provided by health workers in this setting was considerable.

Counteracting dialogues based on patients’ needs or premises, and hence participation in their own health care, was also clearly illustrated in the Norwegian material. In Norway there are regulations, like the Patients’ Rights Act (Helse- og Omsorgsdepartementet [HOD], 1999), which underline a patient’s right to participate in their own health care, including the right to choose between available and medically sound methods of examination and treatment. To be able to ensure such rights patients should receive information necessary to obtain insight into her/his health condition and into the content of care. There are also TB specific guidelines to secure that individually adjusted treatment plans are prepared – to facilitate the treatment (DOT). Still, the findings illustrate that the information is given in ways that do not actively invite patients to take part in decisions about how to organize their treatment. Contrarily, it is given in a way that leaves patients with the impression that there is no room for negotiation; rather there are strong indications of sanctions towards resistance in any form. As argued by Waitzkin (1979), withholding or adjusting information, and implying sanctions, may reduce patients’ subjective sense of autonomy and their objective power to influence their treatment. As in the Ethiopian context, TB patients in Norway remain dependent, vulnerable and powerless.

A study based on interviews with health professionals involved in TB control in various parts of the world found that many interpreted the role of the DOT provider as going beyond observing whether patients actually swallowed their drugs. Especially those working in high-income settings saw DOT as a continuous process of negotiation, in which patients’ individual needs and characteristics were attended to throughout treatment (Macq et al., 2003). However, our study illustrates how authoritarian, less

patient friendly models of DOT can be practiced in both high-income and low-income contexts. Subsequently, this study serves as an example that one cannot assume that DOT implies protection of patient autonomy; not even in contexts where one would expect autonomy to be of high value.

5.4.4 Power structures

Farmer (1999) argues that an understanding of the experience of illness needs to consider the micro level of the individual within the context and influence of macro level structures, processes and interactions. In other words, in order to understand how people interpret and manage TB in different contexts, we need to recognize how larger structural forces limit the patient's ability to access, maintain and complete therapy. Some have claimed that a focus on macro level structures ("structural violence") may lead to few concrete commitments to act (Barnhoorn & van der Geest, 1997). Barnhoorn & van der Geest claim that a key question is whether one should start by trying to change society's unjust structures, or whether one should try to understand, and change, patterns that reproduce such structures at the individual level. There are probably no clear answers to these questions. Still, to prevent some of the barriers and burdens faced by TB patients, there is a need to raise awareness of how processes and interactions between the individual, the community and (representatives of) the health care system, might be shaped by wider, less transparent power structures. A useful analytic tool for describing a patient's experience of being ill is the conceptual framework introduced by Scheper-Hughes and Lock (1987). This framework allows for an understanding of an individual's body from three perspectives; as subjects and single bodies, as social bodies, and as subjects influenced by a body politic. Body politic denotes the possible ways an individual and her/his body can be influenced and manipulated by political and economical processes. As pointed to by Farmer (1997), the risk is that individual behavior, adjusted to structural barriers outside the individuals' control, is interpreted as a product of the subjective or the social body. As such, the political body is overseen, and as a result how the political body is influencing the social body and social structures. Further, how these social structures and social interactions influence the individual and the experience of being ill (Scheper-Hughes & Lock, 1987).

In an attempt to understand how macro-level structures of domination and oppression are reproduced in micro-level interactions between individuals, Waitzkin (1979, p.602) uses doctor-patient encounters to illustrate how medicine serves as an institution of social control. Social control is referred to as “mechanisms by which agencies of the society achieve people’s adherence to norms of appropriate behavior”. In line with Trostle (1988) he argues that scientific knowledge is shaped and reinforced by social institutions, and that these social institutions are structural expressions of the power- imbalance that exists between different social classes. He argues that mystification, either through information control or the use of jargon, maintains stratification in the relationship between patients and physicians. Instead of sharing information with fully informed patients the physician maintains the dominance in the interaction, and decreases the patients’ subjective sense of autonomy and objective exercise of power. Thus, existing power structures in the society at large are exercised and maintained in face-to-face interactions between health personnel and patients. These perspectives might help us understand how it is possible to implement and practice authoritarian and patient un-friendly treatment systems like DOT, across cultures. As exemplified in both contexts of our study, the interaction patterns between patients and health care workers are characterized by the power-imbalance that some would say is an inherent part of most health worker-patient relationships. However, the restrictions on civil rights and autonomy, as well as the associated burdens faced by patients, are beyond what one would normally consider as acceptable losses, at least in the western world.

Foucault (1975), points to how a society may respond to an abnormality, like an infectious disease, by declaring a “state of emergency” with subsequent restrictions or withdrawals of individual rights. In public health discourse, members of the middle class have historically been portrayed as possessing the valued qualities of self-denial and self-efficacy. Individuals from the working class on the other hand have been pictured as dirty, lazy, immoral; and without capacity of resisting their inclinations (Lupton, 1995, p.75). Disciplinary measures, including different types of coercive measures, have subsequently primarily been directed towards less-privileged and less powerful members of society. Public health movements have also become increasingly concerned with maintaining the boundaries of populations, preventing those living within the border from being contaminated from those coming from the outside. Thus, not only the poor

and the working class, but also immigrants have increasingly been portrayed as targets in public health discourse and practices (Lupton, 1995, p.38).

Coker (2000, p.25) suggest that a common thread that runs through public health areas like immunization, mental health and infectious diseases like TB, is that coercion always begins with those least able to resist or argue: children, the mentally ill and the poor. At the end of the nineteenth century, there was a shift from controlling TB towards the control of the behavior of those with TB. There was an increasing use of coercive measures, but such measures were not used uniformly, but focused towards the lower classes. In 1904, a physician in Denver, called Henry Sewall said: “TB is a respectable disease if you have money, but without it, it is a mean low-down business” (Coker, 2000, p. 40). Coker draws parallels between the increasing use of coercive measures in the end of the nineteenth century and the use of coercive measures in the 1980 and early 1990 in New York City. New York City was the first to implement DOT, and public health policy allowed health officials to confine those that were assumed to represent a danger to society. Even if this is a context known for its strong focus on autonomy, such measures did not seem to lead to any protests. As in the previous century, those that were involved were poor, homeless, uneducated immigrants; groups without power.

The papers from Ethiopia (I & II) suggest that impoverished, vulnerable patients may hesitate to approach the health personnel with questions or requests of any kind; the power-imbalance being evident and often intentionally maintained by health workers. In the papers from Norway (III & IV) we found that vulnerable patients, often with an unclear residence permit or poor language skills, felt that the distance between themselves and those in charge of their treatment was insurmountable. Even if patients in both contexts were exposed to coercive measures, in which decisions lacked consistency and transparency, and which imposed heavy burdens, few participants argued or resisted in any way. The study shows how participants in both contexts lack advocates or interest in layers of the population with political or economical power. As one of the participants in the Norwegian study remarked; “if the treatment I receive had been given to an influential Norwegian we would have read about it in the newspaper”.

Trostle (1988, p.1300), argues that medical compliance is better understood if viewed as an ideology; “a system of shared beliefs that legitimize certain norms and values at the same time as they claim to be based on empirical truths”. Such ideologies facilitate transformation of power into authority and hence legitimate control. As pointed

to by Hurtig et al., a treatment system like DOT has the effect that focus is placed on patients' failures while, at the same time, one is "masking the failures of the system to enable patients to comply" (Hurtig et al., 1999, p.558). By focusing on patients' behavior, even coercive measures, which assumingly are addressing the problem (patient behavior), may be legitimized. A question to be asked then, is whether such ideologies; with its authoritarian, uniform approach would have been announced and widely implemented if TB was distributed equally between social classes. How would any wealthy layer in any population respond to a request of renouncing rights related to job security, food security, and physical, emotional or social wellbeing? Power is not equally distributed between classes, and neither is the power to resist (Lupton, 1995). A typical TB patient is poor and black, with little power to exercise her or his autonomy in the meeting with social institutions that are structural expressions of the power-imbalance that exists between different social classes. As discussed in paper IV, DOT, as one among many knowledge practices, entails an intervention into individual lives that are already infused with knowledge practices, and individuals may respond within a continuum of appropriation to resistance. Poor people and minority groups may be accustomed to subordinating themselves to authorities, facilitating self-disciplining and subsequent control. Another dimension that may explain lack of resistance is articulated by Lupton (1995, p.46). She argues that the discourse and practices of public health, for a long time, have carried with them moralistic and discriminatory meanings disguised under a utilitarian logic. During the Reformation the prevalent opinion was that sin and immorality were predisposing causes of illness, and such moral undertones can be argued to influence the way we handle diseases today (Coker, 2000, p.34). When diseases seem difficult to control and medicine appears to be ineffective in treating it, ideas of blame that can be traced back to medieval notions of sin and punishment, purity and contagion, may evolve. In line with Coker (2000), she shows how definitions of groups being "dirty" and "contagious"; in need of extra surveillance, for centuries have corresponded with the poor, the working class and immigrants (Lupton, 1995, p.46). With the emphasis DOT has placed on the fault of the individual, there is a risk that such notions will be used to develop certain knowledge practices with the aim that individuals internalize and discipline themselves according to this knowledge. Health workers may be withholding and adjusting information, partly to preserve the power imbalance; partly to facilitate the treatment, and partly to discipline. By the use of subtle threats of

punishment by authorities like the police or even God; cross culturally exemplified in this study (paper II & IV), the purpose of the treatment gets blurred.

It has been argued that a practice that carries major consequences for patients' autonomy and civil rights is shifting its emphasis from prevention of drug resistance to that of policing treatment compliance (Coker, 2000, p.11). Foucault (1975) argues that one of the characteristics of disciplinary societies is that all means of correction aim at creating a subject who obeys without question, and in order to achieve this goal secrecy and control over possible means of punishments is needed. The less control patients have over the disease, its cause and its possible treatment, the easier it is to establish a relationship of domination in which individuals habitually obey. Our study suggests that what our participants had in common was not culture, but TB and powerlessness.

5.5 Ethical questions related to DOT

DOT has been debated from an ethical and human rights perspective. It has been claimed that there has been too little focus on whether the implementation of DOT has been user-friendly, and culturally-sensitive enough, and whether or not enforced daily clinic-based treatments are ethically justifiable (Porter & Ogden, 1999; Lienhardt & Ogden, 2004). Universal DOT has been challenged as an unethical intrusion of patients' autonomy, and as a violation of constitutional claims implying that the least restrictive means are to be used (Hurtig et al., 1999). Questions has been raised addressing power-imbalances between health care workers and the TB infected (Porter & Ogden, 1997; Hurtig et al., 1999); It has been argued that the discourse of DOT is one of domination and control (Coker, 2000; Ogden, 1999), while others have argued that a "marginal intrusion" on patients autonomy, represented by DOT, is justified by the public health benefits that can be achieved (Bayer, Dubler, & Landesman, 1993). It has been claimed that TB control efforts that ignore socio-economic conditions or that require programs that affects patient autonomy in vulnerable populations, may aggravate already existing inequities and inequalities (Verma et al., 2004).

During the last few years the IUATLD and the WHO have made attempts to address some of the ethical issues within TB control. In 2004, IUATLD appointed an Ethics Advisory group to review clinical trials, scientific programmes and policies. This group has produced policies and operational guidelines based on the Helsinki Declaration (Fanning, 2008). In 2008, the WHO's Ethics and Health Team of the

Department of Ethics, Equity, Trade and Human Rights and the Stop TB Department established a WHO Task Force on Addressing Ethical Issues in TB Care and Control Programmes. A WHO document entitled: "Ethical guidance for TB Care and Control Programmes" is meant to be published within 2010 (WHO, 2009f) and to guide stakeholders in implementing TB control programs in an ethical manner.

5.5.1 Ethical frameworks addressing public health interventions

There are several frameworks articulated by ethicists used to assess the justification of public health interventions such as DOT. These frameworks include a loose set of moral considerations and they to a great extent overlap (Childress et al., 2002; Kass, 2001; Upshur, 2002; Bensimon, Ross, & Upshur, 2007). Childress et al. (2002), point to five different principles that need to be weighed when considering ethical concerns of public health interventions:

- Effectiveness (infringing on one or more moral considerations should be based on public scientific evidence that the proposed intervention will do more good than harm)
- Proportionality (benefits of any proposed intervention outweigh any negative features and effects; such as infringement of patient autonomy)
- Necessity (any intervention that raises moral concern, should not go beyond what is necessary to achieve the goal; e.g. provision of incentives versus coercive measures)
- Least infringement (measures implemented should seek to minimize any moral infringements)
- Public justification (public health agents that implement practices or policies that infringe one or several moral considerations have the responsibility to provide solid, transparent explanations and justifications acceptable to the public).

The principles are intended to help decide whether public health measures legitimize overriding values such as individual liberty and justice, in specific cases. Each principle may conflict with each other, and each of the principles may have to yield in certain situations (Childress et al., 2002). The principles have a dynamic and negotiated nature, which facilitates their use in different cultural contexts. As underlined by Childress et al., even though the general moral considerations that are reflected in the principles find

support in various societies and cultures, it is impossible to determine their weights in advance. In some cultures, values such as individual liberty might be valued as much more important than in other cultures. Whenever conflicts arise over concrete public health measures, the most important thing to recognize is the need to balance such general moral considerations in light of the particular context. Upshur (2002) includes the principle of reciprocity in a discussion on relevant ethical principles in public health: If burdens are imposed on a person in order to comply with public health requests, the community should “pay back” by ensuring that burdens like use of time or income are minimized or compensated for. Addressing the principle of reciprocity could help when balancing moral considerations where conflicts arise.

A central ethical issue in TB control has been balancing patients’ rights and autonomy with the protection of the greater public health (Verma et al., 2004). In a critical review of the evidence, ethics and effectiveness in the management of TB, Verma et al. base their discussion on what is considered the primary consideration in many of the ethics framework for public health; the principle of effectiveness and the principle of least restrictive means. They refer to Volmink and Garner’s (2001) systematic review which provides no evidence that DOT improves cure or treatment completions rates, and argue that lack of solid evidence, combined with neglect of use of least restrictive means, are particularly problematic when vulnerable segments of the population are targeted. Verma et al. refer to Kass who states:

“As a rule of thumb, the greater the burden posed by a [public health] program, – for example in terms of costs, constraints on liberty, or targeting particular, already vulnerable segments of the population – the stronger the evidence must be to demonstrate that the program will achieve its goals” (Kass, 2001, p.1776-82).

Even though different moral considerations may be weighed differently in different contexts, we assume that WHO’s global implementation of DOT (and the forthcoming ethical guidelines) are grounded in general moral principles. In the following discussion, I seek to illustrate how different aspects of the ethics of TB treatment needs to be questioned on the basis of two concerns: First, the preservation of dignity in interactions with the health services, and second, the moral and human rights argument to ensure access to treatment by patients as well as remaining healthy after treatment is completed.

I use the concept “autonomy” and “respect for people’s autonomy” in line with the understanding put forward by Beauchamp and Childress (2001). They argue that to respect an autonomous person is, “at a minimum, to acknowledge that person’s right to hold views, and to take actions based on personal values and beliefs” (2001, p.63). This implies that respect for people’s autonomy involves acknowledging peoples decision-making rights, but also to help people build up or maintain their capacities to make autonomous choices. Disrespect for people’s autonomy involves “attitudes and actions that ignore, insult, or demean others’ rights of autonomy” (2001, p.63). Beauchamp and Childress (2001) underline that hardly any person, or any action, will at any stage or situation be fully autonomous, and for an action to qualify as autonomous, it requires “only a substantial degree of understanding and freedom from constraints, and not a full understanding or a complete absence of influence” (2001, p.59). Appropriate criteria of “substantial autonomy” will have to be addressed within specific contexts (Beauchamp & Childress, 2001, p.60).

5.5.2 How do our findings add to the discussion?

We have found that burdens, in terms of indirect and direct costs, and constraints on liberty and autonomy, are affecting vulnerable segments of the population. In Ethiopia (paper I) we found that those who were the most vulnerable, such as the very poor, single mothers, and working immigrants from rural areas, were the ones that struggled the most to live up to the demands of daily clinic attendance. Some of these patients – representing groups that DOT was designed to attend to – were forced to interrupt treatment, and lost access to further treatment and follow-up. In Norway (paper IV) we found the same tendency; the most vulnerable patients, such as those without permanent jobs, were those that had most difficulties in adapting to DOT. In both contexts we have provided examples of how vulnerable patients are deprived of the possibility to participate in their own health care due to the power-imbalance in the patient-health worker interaction. We have suggested that such power-imbalance is reinforced because of the characteristics of the patient group; being poor, illiterate, or having an immigrant status. Other studies have also documented how vulnerable patients may experience new and insurmountable barriers in relation to organization of treatment (DOT) (Munro et al., 2007a). Viewed against a lack of evidence that DOT improves cure or treatment completion rates, we can question to what degree the principle of effectiveness, and the related principles of proportionality and necessity are being addressed. It is difficult to

see that DOT is doing more good than harm when patients that initiate treatment risk being excluded from further treatment and follow-up because they cannot adapt to the system (paper I). It is difficult to see that potential benefits of DOT outweigh any negative features and effects if patients don't have the opportunity to optimize their health while undergoing treatment (paper I). It is difficult to see that DOT outweighs any negative features if patients do not manage to hold on to their jobs or social positions while on treatment (paper I & IV).

Even though there is a lack of evidence of the effectiveness of DOT, standardized DOT has been widely implemented without considering least restrictive means. This also applies for the two different contexts in our study. Least restrictive means imply that one would implement efforts according to a continuum where self management (potentially with some sort of support) where the least restrictive means, and where detention in a health care setting would represent the other end of the spectrum of restriction (Verma, Upshur, Rea, & Benatar, 2004). Or as argued by Coker (2000, p.118); least restrictive means imply that “people must be allowed to fail before being condemned for that failure”. Doyal (2001) has argued that violation of patient autonomy can only be justified if every effort has been made to optimize the success of treatment without such violation. Our material shows that even in a low-endemic, high-income context like Norway, efforts are not being made to optimize the success of treatment without such a violation. On the contrary, patients that clearly express their will to initiate and adhere to TB treatment are forced into a treatment regimen without being allowed to display their willingness to comply and subsequently retain their autonomy throughout treatment (Coker, 2000). Based on our study, it is difficult to see how standardized DOT in any way can be reconciled with the principle of least restrictive means, since it imposes a coercive treatment regimen on patients that initially – and over time – clearly have verbalized and demonstrated their wish to comply (paper IV).

It has, however, been argued that because DOT is standardized, health workers' initial treatment decisions are not violating another ethical principle; the principle of justice: By emphasizing equal treatment for all, acts of discrimination may be prevented (Dubler, Bayer, Landesman, & White, 1992). Another argument has been that it is difficult for health workers to predict who will comply with treatment, and basing selection on socio-demographic variables may lead to discrimination (Iseman, Cohn, & Sbarbaro, 1993). Both these arguments were used to legitimize standardized DOT

among health personnel in Norway (paper IV). However, even though DOT is standardized we found that health authorities still use their professional power to decide whether an individual is within the bounds of the orderly and the normal, and subsequently whether or not to be treated by DOT. Furthermore, evaluation practices conducted by those in power lacked transparency and appeared arbitrary (paper IV), which may reinforce vulnerable patients' feelings of humiliation and disempowerment. As argued by Childress et al. (2002), public health agents that implement practices or policies that infringe on one, or several moral considerations, have the responsibility to provide solid and transparent explanations which are acceptable and understandable to those involved.

Doyal (2001, p.213) underlines that any coercion used in persuading patients to submit to DOT must be balanced with help to “develop the self-respect and self-control necessary for them to optimize their own health in the future”. Our study indicates that the practice of DOT does not encourage such empowerment. In Ethiopia (paper II), we found that patients were not provided with the knowledge necessary to make sense of their own disease and treatment, so that they could ensure future healing and avoid re-infection. Furthermore, the treatment was not adjusted in a way that made it possible to attend to basic needs. This could cause further impoverishment and disempowerment (paper I). In Norway (paper IV) we found that the practice of DOT had consequences for patients' working lives, school attendance, and social lives – and served as a barrier to vulnerable patients' efforts at societal integration.

In both contexts we found that health personnel lacked respect and sensitivity in their meetings with patients. Health workers seemed to lose sight of the individual patient and their lives in their effort to perform one main task; DOT. Emotional distance, combined with lack of continuity, and minimal time use, prevented patients from participating in their own treatment – and could serve as a source of continuous humiliation. The use of unskilled or poorly trained health workers served as another cause of why patients were exposed to undignified and autonomy reducing practices (paper I & IV). As argued by Porter and Ogden (1999), the danger in implementing a target driven program is that health workers may be more focused on achieving these targets than in caring for the patient and their future health and lives. Within this potential conflict also lies the potential abuse of power. Porter and Ogden (1997), argue that health interventions may embody power-imbalances between the receivers and

deliverers of the intervention, in which e.g. the health workers are the ones that decide when, and how the intervention is going to take place. In their discussion they refer to Hall (1992), who argues that even if people give away some degree of autonomy in exchange for a membership in a community, parts of the individual autonomy will still remain. Hall continues by questioning to what extent this part of the autonomy is attended to within public health measures. A practice where patients comply with DOT but still experience being punished for being delayed in collecting the medicines (paper I) is an example of how such residual autonomy is left out of the equation. A practice where patients are denied storing their own medication, even if this implies daily delays to work due to unpredictable home based services (paper IV), is another example. DOT is based on the ideology that all TB patients are potential defaulters, and within that assumption lays the potential for condemnation. One might argue that treating everyone the same is just, but a uniform program that violates patients' autonomy, and that humiliates patients, might first of all confirm that TB patients are poor and powerless, and potentially to be blamed for their own condition. On the basis of our study it seems legitimate to ask whether neglect of care and dignity in the services is legitimized and facilitated by the receivers of DOT representing a group without power.

A related question is whether the disregard of the heavy burdens imposed on vulnerable patients are neglected due to similar power-structures. The principle of reciprocity emphasizes that when persons experience a loss of autonomy to protect the community, the community should "pay back" by ensuring that burdens like use of time or income is compensated for (Upshur, 2002). It is difficult to see that any efforts to compensate for burdens are made when patients are told to walk long distances to access daily treatment no matter how ill they are (paper I). It is difficult to see that efforts to compensate for burdens are made when rigidity in the systems makes it impossible to attend to daily work or social activities (paper I & IV). This study has illustrated that the principle of reciprocity is attended to, to a surprisingly little extent. Surprisingly – because reciprocity should not only be considered as "pay back", but also an assurance of adherence, and subsequently an element of effectiveness. This study provides, disturbingly, many examples of practices that are not ethically sound, and that do not legitimize systematic infringements on not only patients' autonomy, but basic human rights.

5.6 Future challenges

The intertwined problems of delay in seeking treatment and interruption of treatment among individuals with TB are illustrated throughout our study. Patients face burdens, barriers and enablers at different stages of illness and treatment, which are dependent on or reinforced by individual, cultural, social, economic and political factors. Some of these burdens and barriers, faced by TB patients, may not be relieved until society's unjust structures are changed. However, there are processes and interactions between the individual and various parts of the health care system that might, if modified or changed, reduce some of the burdens and limit some of the barriers patients face in their search for health.

5.6.1 Ensuring early diagnosis

Exploring the causal attributions to TB, made by people in different contexts, will facilitate a better understanding of health seeking behavior in all stages of the disease. The causal attributions will not only affect patients' priorities and strategies, but also affect how they psychologically and socially cope with the disease. Waisbord (2007) relates that lessons drawn from anti-stigma interventions in health programs show the need of questioning dominant beliefs about diseases, and the need to provide supportive environments where people feel free to express themselves and their disease. Since the social stigma that is attached to TB seems to represent a barrier in all stages of the disease, questioning dominant beliefs in all parts of the health care system may be an important step in creating an environment where patients are encouraged to seek help.

Many studies have emphasized that when one seeks to change knowledge and practices, building on local beliefs and practices are a more promising course of action than only relying on providing biomedical information that replaces the existing knowledge and practices (Vecchiato, 1997; Waisbord, 2007). This study illustrates the importance of identifying primary or substitute motives behind different practices, since domination, power and exploitation can represent parts of what at first glance can be interpreted as "indigenous knowledge" and "local practices". Within the same line of argumentation, it is important to realize that overlapping explanatory models can be inexpedient and have serious emotional, social and economical consequences for patients.

Health seeking behaviors are often described as governed by factors that patients do not control (Farmer, 1999). To increase such control, patients need to understand their disease, including the logic connection between TB's etiology and its treatment. Patients need to know how TB is transmitted; how early symptoms can be manifested; how the disease may develop; how it can be prevented, and how it can be cured. Even though there are multiple causes of TB, which may correspond with lay explanatory models (such as poverty), the causal concepts that are being addressed through diagnostic procedures and treatment in the professional part of the health care system, should be made available to patients.

Regardless of the kind of knowledge an individual possesses, knowledge in itself will never enable people to overcome the structural and socio-economic barriers that restrain and complicate health seeking behavior. However, increased knowledge may limit the risk of resources being drained from patients due to repeated visits at the same level in the health care system. The findings from Ethiopia are one of many examples that the private sector needs to be formally involved in TB treatment if TB detection rates are to be increased and infectious cases are to be diagnosed as early as possible. This is in line with WHO's Stop TB Strategy (WHO, 2009c), which encourages the engagement of all types of care providers. Special attention should be given to improve TB detection, referral or treatment in sectors where financial incentives may reinforce methods of diagnosis and treatment that are not in accordance with national strategies.

Even if the private sector becomes further involved in TB diagnosis and treatment this might not represent the only solution. People may still end up using a lot of time and resources in their search for a diagnosis among the variety of available services within the health care system. Measures strengthening and improving the public sector in a way that makes it more competitive with the private sector might represent a more sustainable solution. To achieve this, public services must be made more user-friendly. Several studies have shown that unfriendly, disrespectful and poorly motivated health personnel discourage patients from using public health care services (Storla et al., 2008). Health personnel need to be trained in how to communicate and interact with patients in a way that preserves dignity and enhances autonomy. Exploring dominant beliefs among health workers may promote non-judgmental and supportive treatment environments. To avoid stigma and time-use associated with queuing up in public clinics, more flexible opening hours is one adjustment that could change health seeking

patterns within communities. At the same time one might have to invest in providing working conditions or incentives that make public clinics attractive for health workers. By making public TB clinics more accessible, money used for diagnosis and treatment in private clinics can be reallocated to poverty related needs that may occur as a consequence of becoming ill with TB.

Independent of which health sector a patient seeks treatment in, awareness and proper management of early symptoms have potential for improvement in both high-endemic and low-endemic settings. In low-endemic settings doctors need to be trained to adjust their level of suspicion to the migration history of the patient. In high-endemic settings one should be aware that health personnel may understand and practice TB treatment within a traditional framework, and that there might be a need for further training within the perspective on which current TB services are based.

As acknowledged in the WHO's Stop TB strategy (WHO, 2009c) health personnel in low-income settings need access to reliable diagnostic tools. In settings with high rates of HIV/TB co-infections, health personnel can be prevented from making the right diagnosis and prescribing the right treatment due to limited access to tools like mycobacterial culture. Besides causing diagnostic delay, lack of diagnostic tools might complicate the understanding of TB's etiology, as when health workers do not relate to why patients fail to respond to treatment. As demonstrated in this study, lack of such tools may pave the way for – or reinforce – explanations that correspond with stigmatizing explanatory models.

5.6.2 Ensuring treatment and a lasting cure

TB control efforts can derive from a microscopic view or a telescopic view of the disease; efforts can aim at the microbiological or the socio-economic causes. To be able to ensure that people with TB access and complete treatment, and remain healthy, there is a need to acknowledge and respond to both these perspectives. In the late nineteenth century and the early twentieth century there was a clear understanding of the association between TB and poverty, and public health measures had an advocacy approach that focused on improving living conditions among the poor. Scientific advances, such as the discovery of the tubercle bacillus and the discovery of antibiotics, caused a shift from a holistic, advocacy approach towards an individualistic, bio-medical

approach (Gandy & Zumla, 2002). This shift disguised – and has continued to disguise – the societal factors that make people vulnerable to exposure to TB and vulnerable to develop active TB. These are the same societal conditions which produce barriers in accessing, obtaining and maintaining treatment (Farmer, 1997). A precondition to managing TB must be to include the conditions that predispose for the disease, and at the same time seek to adjust the treatment so that the inequalities that do predispose for TB are not reinforced in the meeting with the health services. As illustrated in this study (paper II & IV), poor and otherwise vulnerable people experience a series of interacting crises that accumulate over time, and which affect their possibility to remain under treatment. A rigid, inflexible practice of DOT reinforces such crises and DOT *per se* can add to the chain of structural barriers that patients have to overcome to get cured. The WHO's Stop TB strategy (WHO, 2009c) recognizes the importance of addressing the needs of poor and vulnerable populations. However, a uniform, target driven approach, with little focus on the individual patient, may prevent such efforts. Our study show that a variety of social and economic costs and other burdens change and interplay over time. This can create a type of vulnerability that will not be identified without services that place the focus on the individual patient. To ensure that TB patients get cured – and remains healthy – one must address the complexity of causes, and the coexisting and interacting crises that follows a TB diagnosis; through programs that have a more holistic and process oriented approach.

Besides widening health disparities, burdens associated with treatment may negatively influence existing rationalities and health seeking patters within communities. Studies have found that people's health seeking behaviors are influenced by strict TB control measures. A study from Vietnam found that private practitioners were preferred because they offered flexible and less authoritarian approaches, including non-supervised treatment (Lönnroth, Tran, Thuong, Quy, & Diwan, 2001). Similarly, a study from India found that TB patients resisted strict TB control programs by choosing private practitioners (Fochsen, Deshpande, & Thorson, 2006). A study from Vietnam found self-treatment as a means of avoiding the control exerted by the national TB program (Johansson & Winkvist, 2002). Flexibility and options in the way the treatment is provided, such as choice of own treatment supporter, may help to find manageable solutions for completing treatment. Reminders, such as daily telephone calls, or text messages, combined with pill dispensers and continuity in the follow-up may represent

good solutions in low-endemic/high-income settings. In high-endemic/low-income settings different types of community based DOT, or self-treatment combined with available forms of reminders and close follow-up, represent possible solutions. To ensure sensitivity and avoid humiliating experiences, all treatment supporters/DOT providers, independent of formal status, should receive adequate training. Continuity among treatment supporters may allow patients to display their willingness to comply and subsequently retain their autonomy throughout treatment (Coker, 2000). As illustrated in our study, health workers (or others) that base their approach on distrust are likely to have a paternalistic attitude, which will not encourage mutual involvement in treatment.

A holistic and more comprehensive approach to TB control would include measures such as securing income and access to food while on treatment. In a study from Haiti, Farmer et al. found that when supplemental food and income were provided, mortality rates and cure rates, but also factors such as weight gain and ability to return to work, significantly improved (Farmer, Robin, Ramilus, & Klim, 1991). A study from Kenya found that HIV patients that were enrolled in a food program while on treatment self-reported better adherence, less side effects, a greater ability to satisfy increased appetite, weight gain, recovery of physical strength and increased possibility to resume work. These improvements were found to trigger increased support from family and community members (Byron, Gillespie, & Nangami, 2008). Making food or income support an integral part of TB treatment can therefore be an important step in strengthening already existing support systems. This action could be the first step in acknowledging that treatment with antibiotics addresses only the proximate cause of TB – and not the more distant links in the causal chain (Ho, 2004). Furthermore, making food or income support an integral part of TB treatment can be the first step in acknowledging and addressing the ethical principle of reciprocity. If individuals are required to sacrifice their self-determination for the sake of the wider community, one must seek to minimize burdens by addressing psycho-social, physical or economic costs. Even if access to food and other basic needs are more precarious in high-endemic/low-income countries, our study shows that rigid DOT programs have high costs for vulnerable patients also in low-endemic/high-income settings. Standardized, target driven programs that do not seek to help patients in coping with treatment related burdens may increase the vulnerability among groups already being marginalized, and

short term benefits may not be sustainable. Furthermore, programs that use autonomy reducing strategies fail to empower people so that they will gain more influence on their future health and lives. Even though the WHO's Stop TB strategy (WHO, 2009c) recognizes the empowerment of patients and communities as important components in TB control, the results from our study are not encouraging.

6. Conclusion

In conclusion, this thesis suggests that:

- To understand how people interpret and manage symptoms, causal attributions to TB needs to be explored in the light of cultural, social and economic factors in the society at large.
- Patients' management of TB and its treatment should be understood by viewing the individual as a whole, in which decisions and preferences derive from a wider social context.
- To better understand barriers to long-term treatment adherence, one needs to relate that interruption of treatment can be shaped by past struggles and accrued costs.
- Interventions to ensure early diagnosis and treatment completion should acknowledge the intertwined problems of delay in seeking treatment and interruption of treatment.
- Cross-cultural similarities in the practice of DOT suggest that monitoring and other treatment practices should be viewed in the light of power-structures in the society at large, including the micro-level interactions between actors involved.
- Cross-cultural similarities in the practice of DOT show that one cannot assume that the implementation of DOT – in any context – implies protection of patient autonomy.
- Use of unskilled and poorly trained health personnel is one of the causes why patients are exposed to undignified and autonomy reducing practices. Health personnel need to be trained in how to communicate and interact with patients in a way that preserve dignity and enhance autonomy.
- Programs that violate individual autonomy fail to empower people to gain more influence on their future health and lives. Even though the WHO recognizes empowerment of patients and communities as important components in TB control, this study shows that such empowerment is far from achieved.
- Even though the WHO's Stop TB Strategy has recommended implementation of "community based DOT" in national TB control programs, uniform and authoritarian versions of DOT are still put into practice.

- Inequalities that predispose individuals for TB may be reinforced in the health services. Low-income and vulnerable TB patients may experience a series of interacting crisis that may accumulate over time, and which affect their possibility to remain under treatment. A rigid, inflexible practice of DOT reinforces such crises and DOT *per se* adds to the chain of structural barriers that patients have to overcome to get cured.

There should be efforts to:

- Create supportive environments where people feel free to express themselves and their concerns about the disease. To ensure such environments one needs to question dominant beliefs and attitudes in the health care system and within communities.
- Raise awareness among health professionals about typical and atypical symptoms of TB and to increase health professionals understanding of patients' own interpretation of symptoms. In low-endemic settings doctors need to be trained to adjust their level of suspicion to the migration history of the patient. In high-endemic settings health personnel might need further training within the biomedical perspective.
- Increase awareness among patients on how TB is transmitted, how early symptoms can be manifested, how TB can progress, how TB can prevented, and how TB can be cured.
- Strengthen and improve the public sector in a way that makes it more user-friendly. Investments should be provided to attract qualified health workers.
- Ensure a holistic and context-sensitive approach to TB control that includes identifying and building on existing support mechanisms in the society.
- Avoid disempowering and humiliating practices by organizing treatment in ways that secure continuity and promote concordance models of communication.
- Create structures and decision-making processes where informed patients are able to express their views and negotiate their needs throughout treatment.

- Create TB programs that focus on processes that individuals undergo throughout the course of the disease. A process oriented approach might help health workers stay connected to the individual patient and the promotion of health in a wider sense.
- Establish ethical guidelines to enhance patient autonomy, empowerment and dignity within all TB control measures.

7. Future research

Our study suggests that there is need for research that:

- Explores how people understand and experience TB and its treatment in different contexts. Examining local understanding and management of symptoms may be of particular value in understanding management of TB in different phases of the disease.
- Explores health care seeking patterns within local communities – with the aim of illuminating bottlenecks or cultural, social or economic barriers that may be prevented or modified in order to ensure early diagnosis.
- Examines a wide range of preceding, interacting, and contextual factors that may influence long-term medication adherence. Mapping time-specific and context specific burdens, barriers and facilitators may help develop strategies that may build on and strengthen already existing social support mechanisms.
- Explores how health personnel understand and manage symptoms of TB and where such understanding converges or dissociate with lay explanatory models.
- Explores how policymakers and health personnel understand DOT and on which grounds they implement and practice different variants of DOT.
- Compares different types of organizing treatment in various social and economic contexts. Intervention packages which include a mixture of measures, such as strengthening the competence among health personnel, and securing of livelihood and food during treatment, should be assessed by both quantitative and qualitative methods. More studies from low-endemic countries are needed.
- Examines the effect of the implementation of ethical guidelines in clinic-based TB treatment and in wider TB control efforts.

References

- Addington, W.W. (1979). Patient compliance: The most serious remaining problem in the control for tuberculosis in the United States. *Chest*, 76, 741-743.
- Annandale, E., & Hunt, K. (1998). Accounts of disagreements with doctors. *Social Science & Medicine*, 46, 119-129.
- Barnhoorn, F., & Adriaanse, H. (1992). In search of factors responsible for noncompliance among tuberculosis patients in Wardha District, India. *Social Science & Medicine*, 34, 291-306.
- Barnhoom, F., & van der Geest, S. (1997). [Letter to the editor]. *Social Science & Medicine*, 45(10), 1597-1599.
- Bayer, R., Dubler, N.N., & Landesman, S. (1993). The dual epidemics of tuberculosis and AIDS: Ethical and policy issues in screening and treatment. *The American Journal of Public Health*, 83(5), 649-54.
- Beauchamp, T.L., & Childress, J.H. (2001). *Principles of biomedical ethics* (5th ed.). New York, NY: Oxford University Press.
- Becker, M.H., & Maiman, L.A. (1975). Sociobehavioural determinants of compliance with health and medical care recommendations. *Medical Care*, January, 13(1).
- Becker, M.H. (1990). In Shumaker, S.A., Scron, E.B., & Ockene, J.K. (Eds.), *The handbook of health behaviour change*. (pp. 5-43) New York, NY: Springer Publishing Company.
- Bensimon, C.M., Ross, E.G., & Upshur, M.D. (2007). Evidence and effectiveness in decision-making for quarantine. *The American Journal of Public Health*, 97(Supplement 1). doi: 10.2105/AJPH.2005.077305
- Bhatti, N., Law, M.R., Morris, J.K., Halliday, R., & Moore-Gillon, J. (1995). Increasing incidence of tuberculosis in England and Wales: A study of the likely causes. *British Medical Journal*, 15:310, 967-9.
- Byron, E., Gillespie, S., & Nangami, M. (2008). Integrating nutrition security with treatment of people living with HIV: Lessons from Kenya. *Food Nutrition Bulletin*, 29(2), 87-97.
- Childress, J.F., Faden, R.R., Gaare, R.D., Gostin, L.O., Kahn, J., Bonnie, R.J., Kass, N.E., Mastroianni, A.C., Moreno, J.D., & Nieburg, P. (2002). Public health ethics: Mapping the terrain. *Journal of Law, Medicine & Ethics*, 30 (2), 170-8.
- Christensen-Szalanski, J.J., & Northcraft, G.B. (1985). Patient compliance behaviour: the effects of time on patients' values of treatment regimens. *Social Science & Medicine*, 21, 263-273.

- Coker, R. (2000). *From chaos to coercion*. New York, NY: St Martins Press.
- Coleman, L. M. (1997). Stigma. An Enigma Demystified. In L. Davis (Ed.) *The Disability Studies Reader*, (pp. 141-152) New York, NY; Routledge.
- Comstock G.W. (2000) Epidemiology of Tuberculosis. In L.B. Reichman & B.S. Hershfield (Eds.) *Tuberculosis: A Comprehensive International Approach* (2nd Ed.) (pp. 129-156) New York, NY: Marcel Dekker.
- Corbett, E.L., Marston, B., Churchyard, G.J., & De Cock, K.M. (2006). Tuberculosis in Sub-Saharan Africa: Opportunities, challenges and change in the era of antiretroviral treatment. *Lancet*, 18; 367, 926-937.
- Cox, H.S., Morrow, M., & Deutschmann, P.W. (2008). Long term efficacy of DOTS regimens for tuberculosis: systematic review. *British Medical Journal*, 1;336, 484-487.
- Cuneo, W.D., & Snider, D.E. Jr. (1989). Enhancing patient compliance with tuberculosis therapy. *Clinical Chest Medicine*, 10, 375-380.
- Curry, F.J. (1968). Neighborhood clinics for more effective outpatient treatment of tuberculosis. *New England Journal of Medicine*, 5; 279 (23), 1262-1267.
- Daniel, T.M. (2006). The history of tuberculosis. *Respiratory Medicine*, 100 (11), 1862-1870.
- Davidson, H., Smirnoff, M., Klein, S.J., & Burdick, E. (1999) Patient satisfaction with care at directly observed therapy programs for tuberculosis in New York City. *American Journal of Public Health*, 89 (10), 1567-1570.
- Davis, A. L. (2000). A historical perspective on tuberculosis and its control. In L.B. Reichman, & B.S. Hershfield (Eds.), *Tuberculosis: A comprehensive international approach* (2nd ed.) (pp.3-54) New York, NY: Marcel Dekker.
- Demissie, M. & Kebede, D. (1994). Defaulting from tuberculosis treatment at the Addis Ababa Tuberculosis Centre and factors associated with it. *Ethiopian Medical Journal*, 32, 97-106.
- Demissie, M., Lindtjorn, B., & Berhane, Y. (2002). Patient and health service delay in the diagnosis of pulmonary tuberculosis in Ethiopia. *BMC Public Health*, 2, 23.
- Dickens, C. (1986) *Nicholas Nickleby*. London: Penguin Books.
- Donovan, J., & Blake, D.R. (1992). Patient non-compliance: deviance or reasoned decision making?. *Social Science & Medicine*, 34, 507-513.
- Doyal, L. (2001). Moral problems in the use of coercion in dealing with nonadherence in the diagnosis and treatment of tuberculosis. *Annals of the New York Academy of Sciences*, 953, 208-15.

- Dubler, N.N., Bayer, R., Landesman, S., & White, A. (1992). *Tuberculosis in the 1990s: Ethical, legal, and the public policy issues in screening, treatment, and the protection of those in congregate facilities. A report from the working group on TB and HIV*. In *The tuberculosis revival: individual rights and societal obligations in a time of AIDS*. (pp.1-42). United Hospital Fund of New York, New York.
- Dye, C., Hosseini, M., & Watt, C. (2007). Did we reach the 2005 targets for tuberculosis control? *Bulletin World Health Organization*, 85(5), 364-369.
- Dye, C., Lönnroth, K., Jaramillo, E., Williams, B.G., & Raviglione, M. (2009). Trends in tuberculosis incidence and their determinants in 134 countries. *Bulletin World Health Organisation*, 87(9), 683-691.
- Elliot, J. (2005) *Using narrative in social research: Qualitative and quantitative approaches*. (pp.1-36). London, UK: Sage Publications Ltd.
- Enarson, D.A. (2000). Tuberculosis control in low-income countries. In L.B. Reichman & B.S. Hershfield (Eds.), *Tuberculosis: A comprehensive international approach* (2nd ed.) (pp.55-74). New York, NY: Marcel Dekker.
- Ethiopia. (2010). In *CIA Factbook*. Retrieved from:
<https://www.cia.gov/library/publications/the-world-factbook/geos/et.html>
- Fanning, A. (2008). An ethical consideration of TB: Still 'a social disease with a medical aspect'?. *International Journal of Tuberculosis and Lung Disease*, 12(3), 229.
- Farah, M.G., Rygh, J.H., Steen, T.W., Selmer, R., Heldal, E., & Bjune, G. (2006). Patient and health care system delays in the start of tuberculosis treatment in Norway. *BMC Infectious Disease*, 6, 33.
- Farah, M.G., Tverdal, A., Steen, T.W., Heldal, E., Brantsæter, A.B., & Bjune, G. (2005). Treatment outcome of new culture positive pulmonary tuberculosis in Norway. *BMC Public Health*, 7;5 (1), 14.
- Farmer, P. (1997). Social scientists and the new tuberculosis. *Social Science & Medicine*, 44(3), 347-58.
- Farmer, P. (1999). *Infections and Inequalities: The Modern Plagues*. Berkeley, CA: University of California Press.
- Farmer, P., Robin, S., Ramilus, S.L., & Kim, J.Y. (1991). Tuberculosis, poverty, and "compliance": Lessons from rural Haiti. *Seminars in Respiratory Infections*, 6(4), 254-260.
- Fochsen, G., Deshpande, K., & Thorson, A. (2006). Power imbalance and consumerism in the doctor patient relationship: Health care provider's experiences of patient

- encounters in a rural district in India. *Qualitative Health Research*, 16(9), 1236-1251.
- Ford, N., Nachega, J.B., Engel, M.E., & Mills, E.J. (2009). Directly observed antiretroviral therapy: A systematic review and meta-analysis of randomized clinical trials. *Lancet*, 19; 374, 2064-2071.
- Forget, E.J., & Menzies, D. Adverse reactions to first-line antituberculosis drugs. *Expert Opinion on Drug Safety*, 5(2), 231-49.
- Foucault, M. (1975). *Discipline and Punish: the Birth of the Prison*. New York, NY: Random House.
- Gandy, M., & Zumla, A. (2002). The resurgence of disease: Social and historical perspectives on the 'new' tuberculosis. *Social Science & Medicine*, 55(3), 385-96.
- Getahun, H. & Aragaw, D. (2001). Tuberculosis in rural northwest Ethiopia: community perspective. *Ethiopian Medical Journal*, 39, 283-291.
- Giorgi, A. (1985). Sketch of a psychological phenomenological method. In A. Giorgi (Ed.), *Phenomenology and psychological research* (pp. 8-22). Pittsburgh, PA: Duquesne University Press.
- Goffman, E. (1968). *Stigma: notes on the management of spoiled identity*. London: Penguin Books, 1968.
- Good, B.J. (1994). *Medicine, rationality and experience. An anthropological perspective*. New York, NY: Cambridge University Press.
- Grant, A., Gothard, P., & Thwaites, G. (2008). Managing drug resistant tuberculosis. *British Medical Journal*, 28; 337. doi: 10.1136/bmj.a1110
- Gupta, K.B., Gupta, R., Atreja, A., Verma, M., & Vishvkarma, S. (2009) Tuberculosis and nutrition. *Lung India*, 26(1), 9-16.
- Hall, S.A. (1992). Should public health respect autonomy? *Journal of Medical Ethics*, 18(14), 197-201.
- Harstad, I., Heldal, E., Steinshamn, S.L., Garåsen, H., Winje, B.A., & Jacobsen, G.W. (2009). Screening and treatment of latent tuberculosis in a cohort of asylum seekers in Norway. *Scandinavian Journal of Public Health*, 13.[Epub ahead of print]
- Haynes, R.B. (1979). Introduction. In: R.B. Haynes, D.W. Taylor, & D.L. Sackett (Eds.) Editors. *Compliance in health care*. (pp. 1-7) Baltimore, MA: The Johns Hopkins University Press.

- Helman, C. G. (1978). "Feed a cold, starve a fever"--folk models of infection in an English suburban community, and their relation to medical treatment. *Culture, Medicine and Psychiatry*, 2, 107-137.
- Ho, M.J. (2004). Sociocultural aspects of tuberculosis: A literature review and a case study of immigrant tuberculosis. *Social Science & Medicine*, 59(4):753-62.
- Helse- og omsorgsdepartementet (HOD). (1999). *The Act of 2 July 1999 No. 63 relating to Patients' Rights. (The Patients' Rights Act)*. Retrieved from: <http://www.regjeringen.no/nb/dep/hod/tema/pasientinformasjon/the-act-of-2-july1999-no-63-relating-to.html?id=229533>
- Homedes, N., & Ugalde, A. (1994) Research on patient compliance in developing countries. *Bulletin of the Pan American Health Organization*, 28(1), 17-33.
- Hurtig, A.K., Porter, J.D., & Ogden, J.A. Tuberculosis control and directly observed therapy from the public health/human rights perspective. *International Journal of Tuberculosis and Lung Disease*, 3(7), 553-560.
- Iseman, M.D., Cohn, D.L., & Sbarbaro, J.A. (1993). Directly observed treatment of tuberculosis: We can't afford not to try it. *The New England Journal of Medicine*, 25; 328(8), 576-578.
- Johansson, E. & Winkvist, A. (2002). Trust and transparency in human encounters in tuberculosis control: lessons learned from Vietnam. *Qualitative Health Research*, 12, 473-491.
- Kamolratanakul, P., Sawert, H., Lertmaharit, S., Kasetjaroen, Y., Akksilp, S., Tulaporn C., Punnachest, K., Na-Songkhla, S., & Payanandana, V. (1999). Randomized controlled trial of directly observed treatment (DOT) for patients with pulmonary tuberculosis in Thailand. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 93(5), 552-557.
- Kass, N.E. (2001). An ethics framework for public health. *The American Journal of Public Health*, 91(11), 1776-82.
- Kleinman, A. (1980). *Patients and healers in the context of culture. An exploration of the borderland between anthropology, medicine, and psychiatry*. Berkeley and Los Angeles, CA: University of California Press.
- Kleinman, A., Das, V., & Lock, M. (1997). (Eds.). *Social suffering*. Berkeley, Los Angeles, London, CA: University of California Press.
- Kvale, S. (1996). *InterViews. An introduction to qualitative research interviewing*. Thousand Oaks, London, New Deli, Sage Publications.

- Liefooghe, R., Baliddawa, J. B., Kipruto, E. M., Vermeire, C., & De Munynck, A. O. (1997). From their own perspective. A Kenyan community's perception of tuberculosis. *Tropical Medicine and International Health*, 2, 809-821.
- Lienhardt, C. (2001). From exposure to disease: the role of environmental factors in susceptibility to and development of tuberculosis. *Epidemiologic Reviews*, 23, 288-301.
- Lienhardt, C., & Ogden, J.A. (2004). Tuberculosis control in low-income countries: have we reached the limits of the universal paradigm?. *Tropical Medicine and International Health*, 9(7), 833-841.
- Lupton, D. (1995). *The imperative of health. Public health and the regulated body*. London; Sage Publications.
- Lönnroth, K., Jaramillo, E., Williams, B.G., Dye, C., & Raviglione, M. (2009). Drivers of tuberculosis epidemics: The role of risk factors and social determinants. *Social Science & Medicine*, 68 (12), 2240-2246.
- Lönnroth, K., Tran, T.U., Thuong, L.M., Quy, H.T., & Diwan, V. (2001). Can I afford free treatment?: Perceived consequences of health care provider choices among people with tuberculosis in Ho Chi Minh City, Vietnam. *Social Science & Medicine*, 52(6), 935-948.
- Maartens, G., & Wilkinson, R.J., (2007). Tuberculosis. *Lancet*, 15; 370, 2030-2043.
- Macq, J.C., Theobald, S., Dick, J., & Dembele, M. (2003). An exploration of the concept of directly observed treatment (DOT) for tuberculosis patients: From a uniform to a customised approach. *International Journal of Tuberculosis and Lung Disease*, 7(2), 103-109.
- Maher, D., Uplekar, M., Blanc, L., & Raviglione, M. (2003). Treatment of tuberculosis. *British Medical Journal*, 11; 327, 822-823.
- Malinowski, B. (1922). *Argonauts of the Western Pacific*. London, UK: Routledge & Keegan.
- Malterud, K. (1993). Shared understanding of the qualitative research process. Guidelines for the medical researcher. *Family Practice*, 10, 201-206.
- Maslow, A. (1943). A theory of human motivation. *Psychological Review*, 50, 370-96.
- Metcalf, E.P., Davies, J.C., Wood, F., & Butler, C.C. (2007). Unwrapping the diagnosis of tuberculosis in primary care: A qualitative study. *British Journal of General Practice*, 57(535), 116-122.

- Michael, K. W., Belachew, T., & Jira, C. (2004). Tuberculosis defaulters from the "dots" regimen in Jimma zone, southwest Ethiopia. *Ethiopian Medical Journal*, 42, 247-253.
- Munro, S. A., Lewin, S. A., Smith, H. J., Engel, M. E., Fretheim, A., & Volmink, J. (2007a). Patient adherence to tuberculosis treatment: a systematic review of qualitative research. *PLoS Medicine*, 4, e238.
- Munro, S., Lewin, S., Swart, T., & Volmink, J.A. (2007b). Review of health behaviour theories: How useful are these for developing interventions to promote long term medication adherence for TB and HIV/AIDS? *BMC Public Health*, 11;7,104.
- Mullen, P.D. (1997). Compliance becomes concordance. *British Medical Journal*, 8: 314, 691-2.
- Murray, C.J., Styblo, K., Rouillon, A. (1990). Tuberculosis in developing countries: burden, intervention and cost. *Bulletin of the International Union Against Tuberculosis and Lung Disease*, 65 (1), 6-24.
- Nair, D. M., George, A., & Chacko, K. T. (1997). Tuberculosis in Bombay: new insight from poor urban patients. *Health Policy and Planning*, 12, 77-85.
- Neher, A. (1991). Maslow's theory of motivation: A critique. *Journal of Humanistic Psychology*, 31; 89. DOI: 10.1177/0022167891313010
- Norway. (2010). In *CIA Factbook*. Retrieved from:
<https://www.cia.gov/library/publications/the-world-factbook/geos/no.html>
- Norwegian Ministry of Labour. (2010). The Norwegian Social Insurance Scheme January 2010. Retrieved from:
http://www.regjeringen.no/upload/AD/publikasjoner/veiledninger_brosjyrer/201/DNT_2010_eng.pdf
- Ogden, J. (1999). Compliance versus adherence: Just a matter of language? The politics and poetics of public health. In J.D.H. Porter, & J.M. Grange (Eds.), *Tuberculosis: An interdisciplinary perspective*. (pp.213-233) London, UK: Imperial College Press.
- Ogden, Rangan, Uplekar, Porter, Brugha, Zwi, & Nyheim. (1999). Shifting the Paradigm in Tuberculosis Control: Illustrations from India. Review article. *International Journal of Tuberculosis and Lung Disease*, 3(10), 855-861.
- Ogden, J., Walt, G., Lush, L. (2003). The politics of 'branding' in policy transfer: the case of DOTS for tuberculosis control. *Social Science & Medicine*, 57(1),179-88.
- Population Reference Bureau. (2007). World Population Data Sheet 3. Retrieved from:
<http://www.scribd.com/doc/326077/World-Population-Datasheet-2007>

- Porter, J.D.H. and Grange, J.M. (1999). *Tuberculosis: An interdisciplinary perspective*. London, UK: Imperial College Press.
- Porter, J.D.H., & Ogden, A. (1997). Ethics of directly observed therapy for the control of infectious diseases. *Bulletin de l'Institut Pasteur*, 95(3), 117-127.
- Porter, J.D., & Ogden, J.A. (1999). Public health, ethics, and tuberculosis: is DOTs a breakthrough or inappropriate strategy in the Indian context? *Issues in Medical Ethics*, 7(3), 79-84.
- Porter, J.D., & Ogden, J.A. (2001). Missed opportunities? Coercion or commitment: policies of prevention. *Annals of the New York Academy of Science*, 953, 224-32.
- QSR international (2009). QSR N7 (NUD*IST 7) [Computer software]. Retrieved from: <http://www.qsrinternational.com/>
- Raviglione, M.C. (2003). The TB epidemic from 1992 to 2002. *Tuberculosis (Edinb)*, 83(1-3), 4-14.
- Reichman, L.B. (1991). The U-shaped curve of concern. *The American Review of Respiratory Disease*, 144(4), 741-2.
- Reichman, L.B. & Hershfield, B.S. (2000). *Tuberculosis: A Comprehensive International Approach* (2nd ed.) New York, NY: Marcel Dekker.
- Reutter, L.I., Stewart, M.J., Veenstra, G., Love, R., Raphael, D., & Makwarimba, E. (2009). "Who do they think we are, anyway?": Perceptions of and responses to poverty stigma. *Qualitative Health Research*, 19(3), 297-311.
- Richards, H.M., & Schwartz, L.J. (2002) Ethics of qualitative research: Are there special issues for health services research?. *Family Practice*, 19(2), 135-139.
- Robinson, I. (1990). Personal narratives, social careers and medical courses: Analyzing life trajectories in autobiographies of people with multiple sclerosis. *Social Science and Medicine*, 30, 1173-1186.
- Roden, J. (2004). Revisiting the Health Belief Model: Nurses applying it to young families and their health promotion needs. *Nursing Health Science*, 6(1), 1-10.
- Rubel, A. J. and Garro, L.C. (1992). Social and Cultural Factors in the Successful Control of Tuberculosis. *Public Health Reports*, 107(6), 626-634.
- Sackett, D.L. & Snow, J.C. (1979) The Magnitude of compliance and Noncompliance. In R.B. Haynes, D.W. Taylor, & D.L. Sackett, (Eds.). *Compliance in health care*. (pp. 11-22) Baltimore, MA: The Johns Hopkins University Press.
- Sanou, A., Dembele, M., Theobald, S., & Macq, J. (2004). Access and adhering to tuberculosis treatment: Barriers faced by patients and communities in Burkina Faso. *International Journal of Tuberculosis and Lung Disease*, 8, 1479-1483.

- Scheper-Hughes, N. (1988). The madness of hunger: Sickness, delirium, and human needs. *Culture, Medicine and Psychiatry*, 12, 429-458.
- Scheper-Hughes, N. and Lock M. (1987). The mindful body: A prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly (NS)*1, 6-41.
- Schouten, B.C., & Meeuwesen, L. (2006). Cultural differences in medical communication: A review of the literature. *Patient Educ Couns*, 66(1),75-83.
- Serkkola A. (1998). Signification and control of tuberculosis in Somali Society: Interaction between chemotherapy and ethnomedicine. *Occasional papers 5. University of Helsinki, Institute of Development Studies*.
- Seymour-Smith, C. (1986). *Macmillan Dictionary of Anthropology*. London, UK: The Macmillan Press Ltd.
- Shargie, E. B. & Lindtjorn, B. (2007). Determinants of treatment adherence among smear-positive pulmonary tuberculosis patients in southern Ethiopia. *PLoS Medicine*, 4, e37.
- Singh, V., Jaiswal, A., Porter, J.D., Ogden, J.A., Sarin, R., Sharma, P.P., Arora, V.K., & Jain, R.C. (2002). TB control, poverty, and vulnerability in Delhi, India. *Tropical Medicine and International Health*, 7(8), 693-700
- Statistics Norway (SSB) (2006). Health accounts, 1997-2005. Retrieved from: http://www.ssb.no/helsesat_en/arkiv/art-2006-05-30-01-en.html
- Statistics Norway (SSB) (2007). Rapport 2007/29. Fakta om 18 innvandrergupper i Norge (Norwegian only). Retrieved from: http://www.ssb.no/emner/02/rapp_200729/
- Statistics Norway (SSB) (2010a). Immigrants and Norwegian-born to immigrant parents, 1 January 2009. Retrieved from: <http://www.ssb.no/en/innvbef/>
- Statistics Norway (SSB) (2010b). Immigration and immigrants. Retrieved from: http://www.ssb.no/english/subjects/00/00/10/innvandring_en/
- Statistics Norway (SSB) (2010c). Rapport 2010/06. Levekår og kjønnsforskjeller blant innvandrere fra ti land (Norwegian only). Retrieved from: http://www.ssb.no/00/02/rapp_201006/
- Stoner, B.P. (1986). Understanding medical systems: Traditional, modern and syncretic health care alternatives in medically pluralistic societies. *Medical Anthropology Quarterly*, 17(2), 44-48.
- Storla, D.G., Yimer, S., & Bjune, G.A. (2008). A systematic review of the delay of diagnosis and treatment of tuberculosis. *BMC Public Health*, 8:15.

- Sumartojo, E. (1993). When tuberculosis treatment fails: A social behavioral account of patient adherence. *The American Review of Respiratory Disease*, 147(5), 1311-1320.
- Tekle, B., Mariam, D. H., & Ali, A. (2002). Defaulting from DOTS and its determinants in three districts of Arsi Zone in Ethiopia. *International Journal of Tuberculosis and Lung Disease*, 6, 573-579.
- Teklu, B. (1984). Reasons for failure in treatment of pulmonary tuberculosis in Ethiopians. *Tubercle*, 65, 17-21.
- Trostle, J.A. (1988). Medical compliance as an ideology. *Social Science & Medicine*, 1988; 27(12), 1299-308.
- Ulin, P., Robinson E., Tolley, E. (2005). *Qualitative methods in public health: A field guide for applied research*. San Francisco, CA: Jossey-Bass.
- UNDP. (2009). *Human Development Report 2009*. Retrieved from: <http://hdrstats.undp.org/en/indicators/81.html>
- Upshur, R.E. (2002). Principles for the justification of public health intervention. *Canadian Journal of Public Health*, 93(2), 101-3.
- Vecchiato, N.L. (1997). Sociocultural Aspects of Tuberculosis Control in Ethiopia. *Medical Anthropology Quarterly*, 11(2), 183-201.
- Verma, G., Upshur, R.E., Rea, E., & Benatar, S.R. (2004). Critical reflections on evidence, ethics and effectiveness in the management of tuberculosis: Public health and global perspectives. *BMC Medical Ethics*, 12;5, E2.
- Volmink, J., & Garner, P. (2007). Directly observed therapy for treating tuberculosis. *Cochrane Database of Systematic Review*, 17; (4), CD003343.
- Waisbord, S. (2007). Beyond the medical-informational model: Recasting the role of communication in tuberculosis control. *Social Science & Medicine*, 65(10), 2130-2134.
- Waitzkin, H. (1979). Medicine, superstructure and micropolitics. *Social science & Medicine*, 13A (6), 601-9.
- Wallace, R & Wallace, D. (1999). Deindustrialization, inner-city decay, and the hierarchical diffusion of AIDS in the USA: How neoliberal and cold war policies magnified the ecological niche for emerging infections and created a national security crisis. *Environment and planning A*, 31, 113
- Walley, J.D., Khan, M.A., Newell, J.N., & Khan, M.H. (2001). Effectiveness of the direct observation component of DOTS for tuberculosis: A randomized controlled trial in Pakistan. *Lancet*, 3;357, 664-9.

- Wallin, A.M., & Ahlström, G. (2006). Cross-cultural interview studies using interpreters: Systematic literature review. *Journal of Advanced Nursing*, 55(6), 723-35.
- Watkins, R. E. & Plant, A. J. (2004). Pathways to treatment for tuberculosis in Bali: Patient perspectives. *Qualitative Health Research*, 14, 691-703.
- WHO. (2003). *Adherence to long term therapies: Evidence for action*. Geneva. Retrieved from: http://www.emro.who.int/ncd/Publications/adherence_report.pdf
- WHO. (2005). Fact sheet EURO 01/05. *Europeans are still dying of tuberculosis* Retrieved from: <http://www.euro.who.int/document/mediacentre/fswtbd05e.pdf>
- WHO. (2006). *Diagnostic and treatment delay in tuberculosis*. Geneva. Retrieved from: http://www.emro.who.int/publications/Book_Details.asp?ID=539
- WHO. (2007). *Global tuberculosis control: surveillance, planning, financing*. Geneva: World Health Organization.
- WHO (2009a). *Communicable disease; tuberculosis; What is DOTS?*. Retrieved from: http://www.searo.who.int/en/Section10/Section2097/Section2106_10678.html
- WHO. (2009b). *Global tuberculosis control: A short update to the 2009 report*. Retrieved from: http://www.who.int/tb/publications/global_report/2009/update/en/index.html
- WHO. (2009c). *Global tuberculosis control. Epidemiology, strategy, financing; key points*. Retrieved from: http://www.who.int/tb/publications/global_report/2009/key_points/en/
- WHO. (2009d). *Countries: Ethiopia; country profile*. Retrieved from: <http://www.who.int/countries/eth/eth/en/>
- WHO. (2009e). *Countries: Norway*. Retrieved from: <http://www.who.int/countries/nor/en/>
- WHO (2009f) *Ethical issues in tuberculosis care and control*. Retrieved from: <http://www.who.int/tb/challenges/mdr/ethics/en/index.html>
- Willig, C. (2008). *Introducing Qualitative Research in Psychology*. (pp.1-14). New York, NY: Open University Press.
- Winje, B.A., Brantsæter, A.B., Heldal, E., & von der Lippe. (2006a). *Behandlingsresultater for pasienter meldt med tuberkulose*. Retrieved from: http://www.fhi.no/eway/default.aspx?pid=233&trg=MainLeft_5669&MainLeft_5669=5544:61059::0:5667:1:::0:0
- Winje, B.A., Mannsåker, T., Heldal, E., Brantsæter, A.B., & Dahle, U.R. (2006b) *Tuberkulose i Norge 2005 (Norwegian only)*. *MSIS-rapport*, 34 (33).

- Winje, B.A., Mannsåker, T., Heldal, E., & Dahle, U.R. (2007). Tuberkulose i Norge 2006 (Norwegian only). *MSIS-rapport*, 35 (16).
- Winje, B.A., Mannsåker, T., Heldal, E., & Dahle, U.R. (2008). Tuberkulose i Norge 2007(Norwegian only). *MSIS-rapport*, 36 (17).
- Zwarenstein, M., Schoeman, J.H., Vundule, C., Lombard, C.J., & Tatley, M. (1998). Randomised controlled trial of self-supervised and directly observed treatment of tuberculosis. *Lancet*, 24;352, 1340-3.

Appendix A

Interview guide for follow-up group

Interview number -----

Date of interview -----

Patients first visit to clinic -----

First interview

Demographic background

Gender -----

Age -----

Education-----

Civil status-----

Permanent home-address/homeless-----

Occupation-----

Symptom understanding, understanding of own vulnerability/severity, and acting (ca two weeks after diagnosis)

Can you tell me about the period you felt the first signs of being ill?

Possible probes:

What kind of complaints did you have when you decided to go to the TB clinic for the first time?

Can you remember how long you waited before you sought medical help?

What did you think you were suffering from?

Why do you think you got this disease?

You have now started with treatment, do you feel better?

Do you think you are ill now? Why, why not?

Do you think the medicines you receive will cure your illness? Why, why not?

Interaction with the clinic and the health personnel

Was the TB-clinic your first choice when you sought help?

Why? If not, where did you go first? (take account)

Did you discuss your choice with anybody? If yes, who? If no, why not?

Can you tell me what happened when you came to the clinic for the first time?

Possible probes:

Did anybody tell you that you were suffering from TB? If yes, when/ who? If no, what were you told you were suffering from?

How did you react?

Were you told how to get cured?

Did they tell you for how long you had to take medicines?

Did you understand why?

Were you satisfied with the information that you got?

Did you ask questions? If no, why not?

Can you tell me what issues you would have liked to talked about?

After the first meeting with the clinic, how did you feel about going back?

During these 2 weeks at the clinic, have you often talked to the same persons?

Social support (family, spouse, neighborhood, community)

After the first visit at the clinic, did you know that you had TB? If no, did you think you were suffering from something else?

Did you tell anybody? If yes, who? If no, why not?

Possible probes:

If yes; how did this person(s) react?

If yes; did your family/spouse support you to go through the medical treatment?

Why, why not? Did they suggest other alternatives?

If no; how do you think these persons would have reacted?

If no; do you plan to tell your family, spouse, and friends? Why, why not?

Can you take the decision about treatment on your own? If not, who can?

Do people in your community talk about this disease? What do they say?

Why do you think some people with TB don't talk about their disease?

Structural/socio-economic barriers

Where do you collect your medicine? When?

Does the health worker observe you when you swallow the medicine?

If yes, how do you feel about that?

How does this arrangement affect your daily life? (Work, family-life)

Is it difficult for you to collect your medicines? If yes, in what way?

In your opinion, how could this treatment arrangement (DOT) be improved?

Second interview

Illness experience, understanding of own vulnerability/severity, and acting (ca two months after diagnosis)

You have now been on treatment for about 2 months. How do you feel?

Possible probes:

Do you think you are ill now? Why, why not?

How long do you think it will take before you get well?

Have you experienced any good changes in the way you feel?

Do you think this is due to the tablets? If no, what do you think is the reason?

Have you experienced any bad changes in the way you feel (side-effects)?

Do you think this is due to the tablets? If no, what do you think is the reason?

What kind of problems has this disease created for you?

Have you tried any other treatment in this period? Why, why not?

Interaction with the health personnel

Can you tell me something about your experiences while going to the clinic this last month?

Possible probes:

Can you remember any situations that made you feel good at the clinic?

Can you remember any situation that made you feel uncomfortable?

Are you often talking to the same persons when collecting medicines?

Is there any person at the clinic that makes you feel good? Why?

Can you tell me what you usually talk about with the health worker?

What would you have liked to talk about?

Do you feel that you now know more about the disease you are suffering from?

Are there things you still feel insecure about?

Have you asked about these issues? If yes, did things become clearer? If no, why not?

During the last weeks, have you ever considered not to go to the health centre?

Social support (family, spouse, neighborhood, community)

Alternative 1: In the first interview you told me that you had not told your family/spouse about you being ill? Have you told them now? If yes, how did they react? If no, how does this affect your daily life?

Alternative 2: In the first interview you said that you had told your family/spouse about your condition. Has anything changed?

Possible probes:

Have any of your family members or friends suggested another treatment?

Do you have someone that support and encourage you to continue the treatment?

Have you told your neighbors/friends that you have TB? If no, why not? If yes, how did they respond?

Have you got to know any others in the community with the same disease?

Do you think that having TB is different for a woman compared to a man?

Do you think there are any groups in your community that face more difficulties having TB than others? Who? Why?

Have you experienced that people think that TB is a disease to be ashamed of?

Structural/socio-economic barriers

Can you tell me how this treatment arrangement (DOT) affects your daily life?

Possible probes:

Is it difficult for you to collect medicines?

Has anything changed (to the better or worse) since last time we talked?

Has it affected your economy in any way?

In your opinion, how could the arrangements of collecting medicines been improved?

Third interview

Illness experience, understanding of vulnerability/severity, and acting (after about five months on treatment)

You have now been on treatment for about 5 months. How do you feel?

Possible probes:

Do you think you are ill now? Why, why not?

What do you think would have happened if you stopped taking medicines?

Are you still experiencing the good changes you mentioned last time?

Are you still experiencing the bad changes you mentioned last time (side-effects)?

Do you still think this is due to the medicines (or other mentioned reasons)?

Can you tell me how this disease affects your daily life at this point?

How do you feel about going to the clinic every day?

Interaction with the health personnel

Tell me about your experiences going to the clinic these two last months? Has anything changed?

Possible probes:

Can you remember any situation that made you feel good? (At the clinic)

Can you remember any situation that made you feel uncomfortable?

Have you got to know any of the nurses or doctors in particular?

Do you talk to many different health workers? How do you feel about this?

Is there anyone in particular you like to talk to? Why?

Have you experienced that different people tell you different things about your condition or treatment?

Are there still issues that you feel insecure about?

Do you find it easier or more difficult to ask questions now?

Can you tell me some good things about coming to the health centre?

Can you tell me some bad things about coming to the health centre?

Social support

Alternative 1: You told me earlier that you still had not told some family members about your disease? Have you told them now? If yes; how did they respond? If no, how do you hide it?

Alternative 2: You told me earlier that you had told your family/spouse about you being ill. Have you experienced any changes in your relation to them?

Possible probes:

Do you still feel that they support you in going for treatment?

Have any of your relatives suggested that you should stop the treatment?

How is your relation with your neighbors/friends at this point?

Have you got to know any others in the community with the same disease?

Have you experienced that people with TB hide their symptoms from others? Do you know why?

Would be easier to have this disease if people in the community knew more about it?

Structural/socio-economic barriers

Can you tell me how this arrangement (DOT) affects your daily life? (Work, family-life)

Possible probes:

Is it difficult for you to collect your medicines?

Has anything changed to the better or worse since last time we talked? (Economy, support)

Since we last talked, have you considered stop going to the clinic for tablets?

If yes, why? If, no; do you think you will face any problems coming here for another 3 months?

Appendix B

Interview guide for patients who had interrupted treatment

Interview number-----

Date of interview-----

First visit to clinic-----

Periods of interruptions in treatment-----

Last visit to clinic-----

Demographic background

Gender -----

Age -----

Education -----

Civil status -----

Permanent home-address/homeless -----

Occupation -----

Symptom understanding, understanding of vulnerability/severity, and acting

Can you tell me about the period you felt the first signs of being ill?

Possible probes:

What did you think you were suffering from? (Type/name, signs)

How did you think you had got these complaints? (Cause, transmission)

What made you chose to go to the TB-clinic?

Did you try other treatment methods first? Why, why not?

If yes, are you still using this treatment?

How did you feel about taking the tablets?

Did you think this medicine would cure your illness?

Did you experience any good changes in the way you felt physically?

Did you experience any bad changes in the way you felt physically (Side-effects)?

When you stopped going to the clinic, how did you feel at that point? (Cured? Feeling well?)

Did you consider that you could become ill again? Why, why not?

Did you continue or enter another type of treatment?

Do you think you are suffering from TB now? Why, why not?

Social support

Did you discuss how to get well with anybody?

Did you take the decision about going to the TB clinic on your own?

Did anybody support you in going to the TB-clinic the first time? (Who? Why/why not?)

When did you start thinking about not going for your medication anymore?

Can you remember what you were thinking?

Did you take the decision about not going for treatment anymore alone? (If, no who did you discuss it with?)

Can you tell me why you (and others) decided that this was the best thing to do?

Did people in your neighbourhood know that you were suffering from TB at this point?
How? Why, why not?

What do people in your community say about this disease? Do you agree?

Do you think that having TB is different for a woman compared to a man?

Do you think there are any specific groups in your community that face more difficulties having TB than others? Who? Why?

Have you experienced that people think that TB is a disease to be ashamed of?

Interaction with the clinic and the health personnel

Was the TB-clinic your first choice when you sought help? If not, where did you go first? (take account of history)

How did you experience the first meeting with this (public) clinic?

Possible probes:

Who received you? What did they tell you?

Did you understand that you were suffering from TB?

If yes, how did you react? If no, did you get the impression that you were suffering from something else?

Did the doctor/nurse tell you how to get cured?

Did the doctor/nurse tell you how long you had to take medicines?

Did you understand why?

Do you remember how you felt after your first meeting with the clinic?

How did you feel about going back?

During the period when you went to the clinic, did you often talk to the same persons?
What did you usually talk about with the health worker?

Were there issues you would have liked to talk more about?

Did you learn more about TB after you started going to the clinic?

Did you feel that you could ask questions about the issues you were insecure about?

From your experience, can you tell me something good about going to the TB-clinic?
(Can you remember a situation that made you feel good?)

From your experience, can you tell me something bad about going to the TB- clinic?
(Can you remember a situation that made you feel uncomfortable?)

Structural/socio-economic barriers

In the period you went to the clinic, can you tell me how having TB affected your daily life? (Work, family-life)

Did anything of importance change? (Relation to spouse, relatives, work etc.)

Possible probes:

Was it in any way difficult for you to collect your medicines? Why, why not?

Did it affect your economy in any way?

Did any good or bad changes occur when you stopped going for treatment?

What would have made it easier for you to continue to take medicines?

Did anyone from the clinic try to contact you when you did not come for treatment the first time? When, how, by whom?

How did the health personnel react when you interrupted the treatment?

Did anyone try to contact you when you dropped out from treatment? When, how, who?

In your opinion, how could the arrangement of collecting medicines been improved?

What would you have done to make sure that all the patients came to the clinic and fulfilled their treatment?

Appendix C

Thematic interview guide - health personnel, Ethiopia

Local perceptions/explanations of the cause of TB (e.g. *bird*)

Local perceptions/management of symptoms

Local perceptions/explanation of prognosis

Local perceptions of *bird* (etiology)

Local perceptions of the connection between *bird* and TB (*samba*)

Local perceptions of the connection between TB and HIV/AIDS

Local perceptions of the concept of “restart” (*megershet*)

Health workers own perceptions

Diagnostic /treatment procedures when patients present with *bird*

Diagnostic/treatment procedures when patients are suspected of having TB

Use of culture tests (treatment, re-treatment)

Diagnostic/treatment procedures when patients are suspected of having HIV

Common side effects/information about side-effects/handling of side-effects

Information to TB patients (when, about what, by whom, follow-up?)

Protein food and healing

Sexual intercourse and healing

Others factors influencing healing? (religious factors)

Reasons for diagnostic delay (any vulnerable groups?)

Use of private clinics (reasons)

Reasons for treatment interruption (vulnerable groups?)

Main questions asked by patients regarding their disease/treatment

Main problems faced by patients during treatment (according to experience)

Stigma/exclusion in the community/support mechanisms (vulnerable groups?)

Suggestion for improvements (DOT)

Appendix D

Interview guide for TB patients – Norway

Interview number-----

Date of interview-----

Interpreter-----

Type of TB/stage of treatment-----

Demographic background

Gender -----

Age -----

Education -----

Civil status -----

Permanent home-address/homeless -----

Occupation -----

Symptom understanding/understanding of vulnerability/severity and acting

Can you tell me about the period you felt the first signs of being ill?

Possible probes:

What types of signs/complaints did you have when you decided to see a doctor (or others)?

Can you remember how long you waited until you sought medical help?

Where did you go? Why?

Did you try other treatment methods first (e.g. cough medicine)

What did you think you were suffering from? (Type/name of disease, signs)

How did you think you had got these complaints? (Cause, transmission)

You are currently under treatment, how do you feel? (Or, you have now completed treatment, how do you feel?)

Do you still think you have TB?

Have you experienced any side-effects (bad changes)?

Do you think the medicines you take will cure you? Why, why not, when?

Interaction with health personnel/experiences related to diagnostic process

Can you tell me what happened the first time you came to the doctor/hospital/emergency room?

Possible probes:

What kind of diseases was mentioned/considered by the health worker?

How did you react?

If TB was diagnosed/considered, did you talk about the length of treatment?

Were you satisfied with the information you got?

Were you satisfied with the tests/diagnostic procedures that were initiated?

Did you ask questions? If no, why not?

Can you tell me what happened after the first visit to the doctor/hospital/emergency room? (Diagnostic procedures, final diagnosis, hospital stay)

If admitted to hospital: Can you tell me about your experiences during the hospital admission? (isolation)

Information/understanding of disease and treatment

Can you tell me about the planning meeting that took place at the hospital? (planning of treatment, DOT)

Possible probes:

How did you feel during this meeting?

Did you ask questions? Why, why not?

Did you manage to convey what was important for you?

Can you tell me what you knew about TB and its treatment before you got ill?
(cause/treatment/prognosis)

Can you tell me what you know about TB and the treatment now?

Are you satisfied with the information that you have got? Why, why not?

Social support

How did you react when you received the TB diagnosis?

Did you tell anyone? If yes, who? If no, why not?

Possible probes:

If yes, how did this person(s) respond?

If no, why not? How do you think they would have reacted?

If no, do you plan on telling people (friends, neighbors) later on?

Have people around you changed in any way after you got TB? How?

What kind of support do you feel that you need?

What kind of support do you experience that you get?

Possible probes:

Have you had any negative experiences related to the fact that you have TB?

Have you had any positive experiences related to the fact that you have TB?

Perceptions/experiences with the treatment (DOT)

Can you tell me about your experiences with the treatment you received at home (DOT)?

Possible probes:

How did the plan (treatment plan) that was made at the planning meeting work?

Have the plan been evaluated/adjusted?

Do you feel that you have received enough information about the disease and the organization of treatment?

Are there still issues that are unclear?

Have the organization of treatment (DOT) affected your life in any way? (socially, practically, economically)?

Possible probes:

Where do you get your medication (at home, at home-based services)

At what point during the day? Every day?

How long time do you use on a daily basis?

What has been good, not so good? (information, continuity etc)

Can you tell me about a situation where you felt good?

Can you tell me about a situation you felt uncomfortable?

Why do you think health personnel want to see that you take your medication?

Can you say anything about how your experience of being observed while taking the medication?

Appendix E

Thematic guide - health personnel in Norway

TB treatment – system level

Present work, experience with TB related work (type, length, responsibility)

Cooperation between primary health care services, hospitals, TB coordinators (float? problems?)

TB coordinators role/position (important, redundant, accepted?)

Intention behind DOT(S)? Foundation of the implementation (regulation, law, binding, guiding?)

DOT - a coercive measure? (as perceived by present health worker, others, why, why not?)

Patient groups being treated under DOT (pulmonary, extra-pulmonary, preventive treatment, selection?). Why these groups?

Changes in TB control after the implementation of DOTS in Norway in 2003 (what changes, why, how?)

Elements of TB control in Norway which could be improved (what works well, less well, DOT in particular)

Experiences with the home based services (quality of services)

Other potential ways of organizing DOT? (why, why not)

TB treatment – individual level

Experiences in relation to how TB patients relate to their disease (cause, treatment, prognosis, stigma)

Experiences in relation to how relatives relate to TB (how do patients relate to the relatives)

Experiences in relation to how TB patients relate to DOT (any differences related to sex, age, country of origin, education level etc?)

Experience of barriers/burdens faced by TB patients (due to the organization of treatment)

Role of TB coordinators, others, to prevent/modify potential barriers

Information that patients need (disease, treatment, DOT)

How, when, by whom are information given? Information needs covered? (why, why not)

Follow-up during treatment. Continuity? Follow-up talks? (primary nurse, primary hospital doctor?)

Practice of DOT throughout treatment (flexibility, choice of DOT provider, assessment over time, use of pill-dispenser)

Standardized DOT versus DOT based on personal needs (pros, cons)

DOT in the intensive phase, DOT all throughout treatment (pros, cons)

Essential elements needed to secure a well functioning treatment system (all parties)

Ethical concerns

Any ethical dilemma's due to the implementation/practice of DOT? (patients' autonomy, self-esteem, dignity, burdens)

Example for discussion: Some of the patients have claimed that it would have been more debate about DOT if the treatment (to a further extent) had involved ethnic Norwegian. Do you agree?

Problems/ethical challenges related to equal treatment (no prior assessment)

Problems/ethical challenges related to flexible, individually adjusted DOT

Errata

In paper III (Experiences of being diagnosed with tuberculosis among immigrants in Norway – Factors associated with diagnostic delay: A qualitative study), page 2, in the paragraph “Participants and data collection”, line 8: “....highest incidence rates in 2005 and 2006 were found among people from Somalia and Ethiopia”, should be corrected to “...the number of reported TB cases in 2005 and 2006 were highest among people who originated from Somalia and Ethiopia.”

Paper I

Research article

Open Access

Barriers and enablers in the management of tuberculosis treatment in Addis Ababa, Ethiopia: a qualitative study

Mette Sagbakken*¹, Jan C Frich² and Gunnar Bjune³

Address: ¹Section for International Health, Institute of General Practice and Community Medicine, University of Oslo, P.O. Box 1130 Blindern, NO-0318 Oslo, Norway, ²Research Unit for General Practice, Institute of General Practice and Community Medicine, University of Oslo, Norway and ³Section for International Health, Institute of General Practice and Community Medicine, University of Oslo, Oslo, Norway

Email: Mette Sagbakken* - mette.sagbakken@medisin.uio.no; Jan C Frich - j.c.d.frich@medisin.uio.no;

Gunnar Bjune - g.a.bjune@medisin.uio.no

* Corresponding author

Published: 11 January 2008

Received: 1 May 2007

BMC Public Health 2008, 8:11 doi:10.1186/1471-2458-8-11

Accepted: 11 January 2008

This article is available from: <http://www.biomedcentral.com/1471-2458/8/11>

© 2008 Sagbakken et al; licensee BioMed Central Ltd.

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/2.0>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Abstract

Background: Non-adherence to tuberculosis (TB) treatment is an important barrier for TB control programs because incomplete treatment may result in prolonged infectiousness, drug resistance, relapse, and death. The aim of the present study is to explore enablers and barriers in the management of TB treatment during the first five months of treatment in Addis Ababa, Ethiopia.

Methods: Qualitative study which included 50 in-depth interviews and two focus groups with TB patients, their relatives and health personnel.

Results: We found that loss of employment or the possibility to work led to a chain of interrelated barriers for most TB patients. Daily treatment was time-consuming and physically demanding, and rigid routines at health clinics reinforced many of the emerging problems. Patients with limited access to financial or practical help from relatives or friends experienced that the total costs of attending treatment exceeded their available resources. This was a barrier to adherence already during early stages of treatment. A large group of patients still managed to continue treatment, mainly because relatives or community members provided food, encouragement and sometimes money for transport. Lack of income over time, combined with daily accumulating costs and other struggles, made patients vulnerable to interruption during later stages of treatment. Patients who were poor due to illness or slow progression, and who did not manage to restore their health and social status, were particularly vulnerable to non-adherence. Such patients lost access to essential financial and practical support over time, often because relatives and friends were financially and socially exhausted by supporting them.

Conclusion: Patients' ability to manage TB treatment is a product of dynamic processes, in which social and economic costs and other burdens change and interplay over time. Interventions to facilitate adherence to TB treatment needs to address both time-specific and local factors.

Background

Tuberculosis (TB) is a major public health challenge, with an estimated 8.8 million new cases and 1.7 million deaths

in 2003 [1]. 27% of these cases and 31% of the deaths occur in Africa, where case rates continue to rise. The situation in Africa has been attributed to the HIV epidemic

and poorly organized TB control programs [1,2]. Treatment of TB requires access to appropriate health care, but patients may find it difficult to adhere to the intended treatment even if such services are available. Studies from both low- and high-income countries show that between 20% and 50% of patients with TB do not complete treatment regimes [3,4]. Incomplete treatment may result in prolonged infectiousness, drug resistance, relapse, and death [5]. Improvement in treatment outcomes requires a better understanding of the barriers and enablers patients experience during TB treatment. Quantitative and qualitative studies from countries in Asia and Africa point to barriers related to availability and accessibility [6-8], and direct and indirect costs related to treatment [9-12]. Inconvenient routines in health care systems [13-15] and interaction with health personnel may also act as barriers [13,16-18].

In Ethiopia, where there is an increasing incidence of new infectious TB cases [19], quantitative studies from rural areas found that between 6.7% and 20% of patients interrupted treatment and that long distances to the health facilities, poor awareness about the disease and treatment length, side effects and lack of family support are important factors [20-23]. An early case control study from Addis Ababa found that "social problems" and "feeling of improvement" were major causes of treatment interruption [24]. These studies found that most patients interrupted treatment in the third or fourth month.

Few studies have used qualitative methods to explore patients' experiences during different phases of treatment, and to the authors' knowledge the studies on diagnostic delay and treatment interruption in Ethiopia have not been explored further in qualitative research.

WHO has emphasized that an important research area is identifying time points in the treatment that are of importance for different types of adherence strategy [25]. The aim of the present study is to explore enablers and barriers in the management of TB treatment during the first five months of treatment in Addis Ababa, Ethiopia.

Methods

We used qualitative methods to explore enablers and barriers in the management of TB treatment. We found that in-depth interviews conducted during different stages of treatment were the most appropriate method for exploring how context-specific enablers and barriers interact over time. We used focus group discussions for further exploration and validation of information from the in-depth interviews. The study comprised a follow-up study with three individual in-depth interviews of 10 newly-diagnosed TB patients, in addition to one single individual interview with 11 TB patients who had interrupted

treatment. We also interviewed two TB patients who were on re-treatment, four relatives, five health care staff, and conducted focus group discussions involving 11 TB patients currently undergoing treatment.

Study setting

Data was collected over a six-month period in Addis Ababa, the capital of Ethiopia, in 2001–2002. At this time, Addis Ababa had about 95% coverage of directly observed treatment, short course (DOTS) in existing governmental health facilities [26]. TB treatment involved daily attendance for two months (the intensive phase), followed by a period of six months during which medicines were collected once or twice a month (the continuation phase). At the time of the study, HIV counselling and testing was not routinely carried out for TB patients. Anecdotal reports and clinical observations suggested a high rate of co-infections, and according to the Ethiopian Ministry of Health AIDS patients occupied about 42% of existing hospital beds [19,27]. The number of TB patients not completing their full course of treatment was difficult to estimate, as only a proportion of smear-positive patients were evaluated for their outcome [26].

Study sites

Participants were recruited from three sites: (i) Woreda 23 Health Centre, a centre for TB diagnosis and treatment located about two kilometres from the ALERT (All African Leprosy and Rehabilitation Training Centre) hospital; (ii) St Peter's TB Specialized Hospital Outpatient Service, which offered diagnostic and treatment services and was located in the Kolfe area; (iii) and Kebele 16 Health Post, which provided TB treatment but was without diagnostic facilities (patients were diagnosed at Woreda 23 Health Centre). This health post was located in a slum area close to the ALERT hospital and training centre. (A Kebele is part of a Woreda and is the smallest administrative unit in Ethiopia.) These research sites were chosen based on advice from local researchers at Armauer Hansen's Research Institute (AHRI) and from WHO's TB/Leprosy advisor at the Ministry of Health in Ethiopia. The sites were considered to be "typical" DOT (directly observed treatment) clinics, but they were also chosen because they represented diversity being located in different areas of town. The three sites had similar routines related to daily TB treatment (DOT).

Participants and data collection

The study included both TB patients who were attending TB treatment and TB patients who had interrupted TB treatment. Newly diagnosed TB patients ("new cases") were approached by means of an invitation letter distributed by health personnel at Woreda 23 Health Clinic. A purposeful sample of 10 patients; five men and five women aged 18 to 67 years, participated in the prospec-

tive part of the study. Two patients declined to participate because they were too ill. Participants' characteristics are displayed in Table 1. There were difficulties with tracing patients who had interrupted treatment, due to lack of, or incorrect, addresses. St Peter's TB Specialized Hospital Outpatient Service and Kebele 16 Health Post were therefore included for the purpose of recruiting patients who had interrupted treatment. We traced 11 patients that had been on treatment for at least two weeks, and had interrupted treatment for more than six consecutive weeks at the time of contact. All eleven patients agreed to participate in the study. The group consisted of six men and five women, aged 20 to 60 years. Participants' characteristics are displayed in Table 1. The National Tuberculosis and Leprosy Control Program (NTLCP) restricts its definition of defaulters to patients who have attended treatment for at least four weeks and have been absent for at least eight consecutive weeks or for a cumulative period of 12 weeks. All of our participating patients do thus not meet the formal definition of a defaulter. Focus group participants were recruited by the first author and the research assistant from all three clinics.

We developed an interview guide that covered general beliefs about TB and TB treatment, as well as time-specific factors that could affect the management of treatment. The guide was inspired by Becker's [28] review of models and strategies to find consistent predictors of adherence. Becker suggests that certain health beliefs, together with

the psychological and other perceived costs of the recommended action, the interaction between patients and health service deliverers, and other types of social influence, are important dimensions for understanding adherence.

Ethics

Informed oral or written consent was sought in all cases. De-identification and confidentiality were ensured by using numbers and fictitious names to describe and identify patients. Ethical approval for the study was obtained from the Regional Committee for Medical Research Ethics in Norway and the National Ethical Clearance Committee in Ethiopia.

Individual in-depth interviews

The first author (MS) conducted face-to-face, tape-recorded, qualitative, in-depth interviews. The questions and answers were translated from English to Amharic and vice versa by a local research assistant/interpreter. All interviews took place at locations chosen by the patients. The interviews lasted from two to three hours. Questions in the interview guide were open-ended, and emerging themes and hypotheses from earlier interviews were explored in subsequent interviews. 10 TB patients were interviewed three times over a period of five months. The first in-depth interview was conducted two weeks after diagnosis, the second interview two months later and the third interview five months into treatment. All patients, except one who died, participated in all three interviews. A single individual in-depth interview was conducted with each of the 11 patients who had interrupted treatment. Other groups of informants, like relatives of patients that died after treatment interruption, and patients on re-treatment, were also interviewed. In-depth interviews were additionally conducted with two nurses and one doctor from Woreda 23 Health Centre, one nurse from Kebele 16 Health Post and one nurse from St Peter's TB Specialized Hospital Outpatient Service. These individuals were recruited because they were managing TB patients on a full-time basis. Participants' characteristics are displayed in Table 2.

Focus groups

Two focus group discussions with TB patients who were undergoing TB treatment were arranged after the in-depth interviews were completed. Patients with different educational backgrounds were chosen [29], yet with adjustments to personal features and the group composition as a whole. One group consisted of five female TB patients, the other of six male TB patients. Participants' characteristics are displayed in Table 3. The focus group discussions lasted for two hours, and were moderated by the research assistant, who was trained in focus group interview principles and techniques. The first author introduced pre-

Table 1: Characteristics of 10 patients undergoing treatment and 11 patients who had interrupted treatment who were interviewed individually

Characteristic	Undergoing (n = 10) No.	Interrupted (n = 11) No.
Gender		
Male	5	5
Female	5	6
Age		
< 25	3	2
26–35	6	6
> 36	1	3
Education		
Partly illiterate/illiterate	1	4
1–6 years	3	3
7–10 years	1	2
11–13 years	5	2
Occupation		
Daily labourer*	2	3
Civil servant	2	1
Private sector	3	4
Other	3	3

* Person who is not employed on a permanent basis, but who may meet at a regular point every day to compete with others to be hired for the day.

Table 2: Characteristics of 5 health personnel and 6 other participants who were interviewed individually

Characteristic	Health personnel (n = 5) No.	Others (n = 6) No.
Gender		
Male	3	
Female	2	
Education		
Nurse	4	
Medical doctor	1	
Relatives of patients		4
Patients on re-treatment		2

selected topics related to common, discrepant or particularly interesting findings from the in-depth interviews for further validation. Notes were taken, and the discussions were tape-recorded.

Analysis

Use of an interpreter during interviewing creates a potential source of misunderstanding. We actively sought to prevent errors by continuously discussing and negotiating the content of key words, broader concepts and units of meaning. The first author and the research assistant/interpreter thoroughly discussed and clarified the content of each tape-recorded interview. Clarifying notes were added and main themes and issues to be explored in subsequent interviews or focus groups were systematically written down (conceptual maps). A "memo" (notes on each participant, including main content of the interview) was made enabling the second and third author to read about each of the participants that were interviewed and quoted in the manuscript. The research assistant translated and transcribed verbatim each interview and the discussions in the focus groups. All transcriptions were manually coded within a defined coding frame. The coding frame was developed on the basis of Becker's theories [28], and was informed by themes and issues emerging from the material. Data concerning factors that affected patients' management of TB treatment was used for systematic text condensation, according to the principles of Giorgi's [30] phenomenological analysis, modified by Malterud [31]. The analysis followed these steps: (i) reading all the material to get an overall impression; (ii) identifying units of meaning that represent different factors that influence the management of TB treatment, and coding for these; (iii) condensing and summarizing the content of each of the coded groups; (iv) integrating the insights from the condensed meaning units into generalized descriptions that reflect apparently significant factors. The analysis was summarized and accounted for in an analysis document that all authors commented on.

Table 3: Characteristics of 11 patients who were undergoing treatment and who were interviewed in focus groups

Characteristic	No.
Gender	
Male	6
Female	5
Age	
< 25	4
26–35	4
> 36	3
Education	
Partly illiterate/illiterate	2
1–6 years	3
7–10 years	4
11–13 years	2
Occupation	
Daily labourer	3
Civil servant	3
Private sector	2
Other	3

Results

We found that loss of employment or the possibility to work led to a chain of interrelated barriers for most TB patients. Daily treatment was time consuming and physically demanding, and rigid routines at health clinics reinforced many of the emerging problems. Patients with limited access to financial or practical help from relatives or friends experienced that the total costs of attending treatment exceeded their available resources. This was a barrier to adherence already during early stages of treatment. A large group of patients still managed to continue treatment, mainly because relatives or community members provided food, encouragement and sometimes money for transport. Lack of income over time, combined with daily accumulating costs and other struggles, made patients vulnerable to interruption during later stages of treatment. Patients who were poor due to illness or slow progression, and who did not manage to restore their health and social status, were particularly vulnerable to non-adherence. Such patients lost access to essential financial and practical support over time, often because relatives and friends were financially and socially exhausted by supporting them. These findings are grouped into main themes and examined in further detail below.

Loss of income

The majority of patients in the study experienced loss of employment or the opportunity to work as one of their main problems during treatment. Patients reported losing their job when their TB diagnosis was known, or because they were too ill to continue working, or were unable to find daily work because of the time consuming treatment arrangements. Three patients were housewives, but the

household finances were still affected because their husbands lost income and risked their jobs escorting them to the clinic. One of the husbands explained:

"I tried to explain for them that I was the only one working in our family, so I couldn't go every morning ... because in that way I would lose my job and me and my wife would die of hunger. I work in the private sector and it is difficult to get permission every day." (Participant 24, prospective group.)

Patients who worked in the private sector and "daily labourers" (a person who is not employed on a permanent basis, but who may meet at a regular point every day to compete with others to be hired for the day) were most affected. Also health personnel identified these groups as particularly vulnerable:

"People who are daily labourers or work in the private sector they can't get any kind of [sick] leave and they face more problems. Many of them interrupt treatment because they don't want to lose their jobs. They rather live for a while, with money and their jobs, to eat and then die." (Participant 27, male nurse.)

Being ill and without access to any health care benefits often resulted in a loss of income from one day to the next. Patients' situations were aggravated because loss of income coincided with additional expenses. More than half of all the patients had been treated at private clinics before entering conventional TB treatment, paid for from savings or money borrowed from relatives or community members. Daily attendance at a clinic caused high transportation costs, and those that could not afford transportation incurred opportunity costs due to extensive time use. In addition, most patients believed that they had to eat expensive protein food like meat, milk and eggs to get cured. A daily labourer offered an illustration of how the struggle to obtain "good food" increased his already pronounced personal crisis caused by loss of income:

"How can I get this food [good food], it is impossible to get this. I don't have a job. [...] I'm even considering committing suicide. [...] I have lost all hope ... totally. I am the one that support me and now I can't support myself. I can't work, and then it is hard for me to survive." (Participant 10, male patient, prospective group.)

Loss of income combined with additional costs made TB patients' particularly vulnerable during the first period of treatment (the intensive phase). Two patients in the prospective group continuously considered interrupting treatment due to a lack of money for food and transportation to the clinic.

Hunger

Impoverishment due to loss of income caused unpredictability and emotional stress in relation to daily access to food. Many participants described feeling chronically hungry, suffering the slow starvation of people who eat a little bit every day but whose hunger is never fully satisfied. A young male patient, who lived with his single, TB inflicted mother, was too ill to continue working as a daily labourer. He related how lack of food made him lose his motivation to follow the treatment:

"Q. During the last weeks, have you ever considered not to go to the health centre?"

"Yes, I thought about that many times ... on and off. Especially when I lack food I feel like not coming. [...] My only motivation is to get food ... food ... it is food that is motivating me [...] to get food, any kinds of food ... at the right time ... and to have a person that can help you get that food." (Participant 8, male patient, prospective group.)

Chronic hunger induced a feeling of hopelessness among patients. Irregular and insecure access to food over time made many lose their hope of recovering and avoiding death.

Taking medicines on an empty stomach

Gastritis was the most common side effect, and was reported by nearly all intensive-phase patients. The symptoms were described as a burning or gnawing pain in the abdomen. A few patients explained that they pretended to swallow the medicines, saving them until they could take them with food or milk. A female focus group participant explained:

"I knew that I would feel the pain if I swallowed the tablets immediately [at the clinic]. Therefore I pretended swallowing the tablets. I took the tablets, hiding them. Then I swallowed the tablets later ... with milk ... at home." (Female focus group participant, focus group one.)

Patients attributed side effects, such as gastritis, nausea, and vomiting, to taking strong medicines on an empty stomach. These side effects had a large psychological impact: Since most patients considered access to food, and particularly food with a high content of protein, as extremely important to healing, symptoms as gastritis served as a continuous reminder of their poverty and what they considered to be poor healing conditions.

Physical demands

Most patients complained that the first two months of treatment were physically exhausting. This was particularly the case for the many patients who were at advanced stages of the disease at the time they started treatment.

Patients attending treatment at Kebele 16 Health Post had shorter walking distances than those attending the other clinics. This was a tremendous advantage for the many who could not afford transportation. Most patients from the other two clinics reported using one to two hours each way. A patient with advanced symptoms, and who was also suffering from various side effects, described her daily walk to the clinic:

"Q. Do you always walk or do you take any kind of transport?"

P. "I walk, I don't have any money for transport."

"Q. Is it hard?"

P. "Yes, it is a bit far. I use almost two hours and I vomit on the way." (Participant 5, female patient, prospective group.)

Once at the clinic, patients often waited an hour or more to get their medication. This delay was mainly caused by intensive-phase patients being told to attend at the same time in the morning. This time-consuming system was described as humiliating by some of the patients.

Rigid routines and health staff attitudes

The three clinics in the study practised DOT without taking into consideration that many patients were not physically able to come to the clinic. Many patients told how they had begged to be hospitalized, but due to a lack of hospital beds this option was out of the question for many. One patient died on the 59th day of treatment, having been refused medical attendance before the 60th day, in accordance with clinic routines. Her husband described how they had struggled to make health personnel understand that she was far too ill to walk to the clinic:

"We went to the clinic to ask if the nurse could give her the medicines, at least once in seven days, telling him that our house was far away [...] and explaining them that she was too weak to go to the clinic every day ... she couldn't walk at that time. The nurse didn't understand, rather he threatened her saying he would demand her to come and collect the medicines no matter how ill she was." (Participant 24, prospective group.)

In a few cases, relatives were allowed to collect the medicines on behalf of very ill patients. This, however, put the relatives' jobs in jeopardy, as they had to queue at the clinic every day. In most cases, the patients were escorted to the clinic by relatives. This incurred transportation and opportunity costs for two persons, often within the same household. The clinics allowed no exceptions for family- or cultural events, and were highly inflexible as regards patients trying to combine daily treatment with work-related activities. Only one patient in the prospective group managed to hold on to his job. He explained the

repeated difficulties he faced trying to balance the demands of work with the treatment arrangements:

"Once I came late and I met the bad nurse ... and he was angry about it. He told me to sit and wait for him until he got back from town, just to give me my medicines. After he warned me not to come late anymore and then he gave me the medicines. He said, 'next time you will be given the injections even later and you will be very late for your work'." (Participant 6, male patient, prospective group.)

Some nurses were more flexible than others, but there were examples from all three clinics of patients who were threatened, humiliated or treated angrily by staff for not adhering to the implicit rules of the system. At one of the clinics, two patients reported that they had been denied access after a period of interruption.

Dynamics of social support

The support of family and community members was extremely important during the intensive phase of treatment, because this to a large extent compensated for loss of income. Even though TB caused fear and stigmatization, people shared resources in a time of crisis, and reciprocal arrangements provided most TB patients with some food. Many received physical support in walking to the clinic, and some received money for transportation. A male patient who lost his job as a car washer explained how the contributions of relatives and community members helped him:

"Even if I can't get good food I try to get as much food as possible. People who visit me bring me food ... neighbours and relatives." (Participant 9, male patient, prospective group.)

Many patients experienced changes in the level of support as the treatment program progressed. A male patient, who lost his job as a temporary teacher, moved to live with relatives in a rural area after completing the intensive phase. His friends and grandmother no longer had the means to help him:

"She [grandmother] couldn't afford to help me anymore. She couldn't help me because of her shortage. They are all fed up [...] I have moved, walked from place to place ... and there is no food. In the rural area, even if my father is poor, I at least managed to get milk from the neighbourhood." (Participant 1, male patient, prospective group.)

Many patients faced difficult situations after completing the intensive phase of treatment, as the levels of support dropped. Both patients and health personnel reported that the causes of the changes in support levels were closely related to practical and symbolic changes in treatment at this stage.

Crisis precipitated due to completion of the intensive phase

Based on a synthesis of the various sources of data we found completion of the first phase of treatment to precipitate changes, often critically affecting existing support mechanisms: First, patients were expected to stop going for treatment on a daily basis, and were not expected to need money for transport or help with walking to the clinics. These changes reduced the attention focused on their difficulties, and their needs therefore became less visible. Second, it was expected that the health status of patients who had finished the streptomycin injections, which were considered the "main" medicine, should improve significantly. Third, physical improvement was associated with the expectation that patients would start to work again. Fourth, the foods provided from the community were expected to make a physical difference in patients. There is a strong association between TB and HIV/AIDS, and patients with a "curable disease" are expected to gain weight and strength within a certain period of time. Patients with prolonged disease (intermittent symptoms or no weight gain) may be treated as having an incurable disease (AIDS or a "chronic" type of TB), a condition that carries additional stigma.

Six out of 10 patients in the prospective group, all still financially dependent on others, experienced increasing problems in mobilizing enough help in the period between the second and fifth months. Some gradually received less food, others were told to leave the house because they were no longer able to contribute with the rent. The experience of one patient, who still displayed symptoms as skinniness and weakness during the continuation phase, is illuminating. He reported how his relationship with his brother and sister-in-law became increasingly tense because he could no longer pay his share of the food and rent. He was told to leave in his fifth month of treatment:

"People will get bored of you. Earlier they supported me when they had money, or with some food, but they don't do that much more. I can't ask for help all the time. (Crying) It is at home ... they have asked me to leave their house now." (Participant 10, male patient, prospective group.)

Relatives and community members may start to interpret the slow recuperation process negatively, as indicating eventual death, or they may assume that the patient will not manage to re-establish his or her income. The basis of reciprocity is taken away both when a patient becomes totally dependent either permanently or for a prolonged period of time, and when people think that the patient is dying. When health personnel were asked about their experiences related to treatment interruption, they all mentioned patients leaving to live with relatives in rural

areas as one of the main causes. This was seen as a consequence of patient-relative relationships being financially or emotionally exhausted in the later stages of treatment.

Interplay of factors

Attending TB treatment brought with it various struggles to meet the physical, psychological and financial costs of treatment. Interviews with patients who had interrupted treatment also demonstrated the interplay of such factors. Five patients interrupted during the intensive phase of treatment, two of them with only a few days left. Six patients interrupted between the third and sixth months of the continuation phase. Only one patient pointed to a single factor as the cause of treatment interruption. This patient was denied a sufficient ration of medicine to enable her to travel to the place where her son just had been murdered. The causes of interruption were different, but interrelated. They often operated over time and were most often related to financial constraints. Three examples that illustrate identifiable patterns in treatment interruption are presented below.

Case one

A single mother, a working immigrant from a rural area, used to beg outside one particular church before and after morning mass. She had a small but regular income from regular church visitors. Due to DOT, which takes up the morning hours, she couldn't do that anymore, and her only source of income was dramatically reduced. As a result, she was unable to pay for the room she rented, and she and her baby ended up on the street. She turned to the health personnel, telling them that she was starving and that she needed to take the medicines with her to her mother in the countryside. Her request was denied, and she decided to leave without the medicines after two weeks of treatment:

"I didn't intend to interrupt the medicines at that time, but I was too poor to keep on taking the medication. I was told to eat eggs, meat and to drink milk, but the truth was ... I didn't even have injera [Ethiopian pancake]. I went to the countryside because I was forced to go there." (Participant 19, female patient, retrospective group.)

This case illustrates how poor patients without rights to paid sick leave or access to financial support from family and friends experience acute and unbearable financial crises during early stages of treatment.

Case two

A male TB patient interrupted treatment shortly before completing the intensive phase. During treatment, he made intensive efforts to find daily work, but his physical condition and the time-consuming system made this difficult. He often had no money for transport, and he felt

weak and tired from having to walk four kilometres twice a day. Sometimes he was late for treatment, which made the health personnel angry. After about a month and a half, he experienced that the friends who had helped him the most became more reluctant to support him with money. At the same time his relatives, all living in a rural area, invited him to a funeral. He asked the health personnel to be allowed to attend, but this request was denied. He decided to leave, interrupting treatment. When asked why he interrupted, he gave several reasons:

"P. I didn't finish the treatment because I had to work to get food and I was told to eat anything possible for the medication and for the disease ... otherwise the medicines can't work ... and to get food I had to work. The other thing was that I didn't have money for transport to come to the clinic and I couldn't walk always because I would be too late by the time I arrived at the clinic. [...] I felt weak by walking to the clinic everyday, and the insult of health personnel discouraged me.

Q. Would you say this whole situation made you go to your relatives?

P. I went there because I was obliged to go there. (Pause) But I was not motivated to come on foot to the hospital anymore." (Participant 13, male patient, retrospective group.)

This case illustrates the situation where a patient ends up in a vicious circle, where the demands of treatment become more and more difficult to handle. A funeral or a sick relative then represents a breaking point; a legitimate way out of daily and accumulating struggles.

Case three

A young girl interrupted treatment after four and a half months. At the time she started the medication, she was too ill to walk to the clinic, and her mother collected the medicines every day on her behalf. The time the mother spent on daily attendance and nursing her daughter made it impossible for her to work, and both mother and daughter became totally dependent on food provided by their neighbours. After two months of daily treatment, the community members expected them to manage on their own again. However, re-establishing herself as a beggar and laundry washer proved difficult for the mother, and as she was the only breadwinner, she became unable to feed all her children. Desperation and hunger made the sick girl break with the established social norms of the community by begging in her own neighbourhood. This led to unbearable fights with her mother:

"I started with the treatment, but after a while I felt so hungry and the shortage of food at home ... and because I felt like mentally disturbed taking the medication ... made it impossible for me to continue. On top of that my mother treated me so badly

at home. To overcome the shortage of food at home I started to beg food and money from the neighbourhood. This begging thing made my mother really mad. She said I was humiliating her. We had some really big fights and after that I escaped from home." (Participant 21, female patient, retrospective group.)

This case illustrates how prolonged illness may affect relations with relatives and community members. Weeks or months of involuntary dependency force patients into humiliating situations, while relatives and friends may suffer from social or financial exhaustion.

Discussion

What does this study add to previous knowledge?

This study suggests that patients' management of treatment is a product of dynamic processes and that patient's behaviours respond to the complex patterns of socio-economic and psychological factors during the course of treatment.

The effect of time per se on adherence behaviour is described by Christensen-Szalanski and Northcraft [32]. They point to the importance of understanding patients' temporal perception of costs and benefits, and how temporal perceptions may be influenced by delayed benefits and accrued costs. We found that most patients experience a chain of interrelated barriers during the intensive phase of treatment. This chain is often activated by loss of income and followed by lack of money for transport; extensive time use; daily physical demands; food insecurity; side effects and hunger. Rigid routines related to daily attendance exacerbate many of these problems. TB patients losing their jobs and the opportunity to work has been reported both in other parts of Ethiopia and in other countries [6,12-14,33,34]. A study from Addis Ababa [35] reported walking distances up to two hours and found that the distances from patients' homes to the health centres contributed to diagnostic delay. The author underlines that the same factor may seriously affect TB patients' ability to attend daily treatment.

We found that barriers in the intensive phase are managed by most patients, albeit in different degrees, partly determined by the extent of financial and practical support from family and neighbours. The protective effects of family support have been found in other studies [6,10,33,36]. One study indicates that initially strong family support became weaker during treatment [14]. Our study suggests that patients who have fewer human or material resources available in their environments, such as the very poor, single mothers, and working immigrants from rural areas, do not benefit from such protective factors. Some of these patients may be forced to change their strategy and, as related in this study, forced to move in with relatives in

other areas due to acute financial crisis that arise even during the early stages of treatment.

We found that a decision to interrupt TB treatment may be taken in response to social obligations, such as attending a funeral. A study from Addis Ababa [24] found illness of relatives and attendance at funerals to be two of the most frequently cited reasons for treatment interruption. Even if such decisions are triggered by strong social norms, they may be shaped by past struggles and accrued costs, which may seem unbearable at the moment the decision is taken. Hungry patients who lack the strength or motivation to continue treatment have also been found elsewhere [37]. Previous studies from Ethiopia have found that most patients interrupt in their third or fourth month of treatment [22-24]. One study [23] found lack of family support to be one of the major causes of interruption, and this is supported by the findings in this study: Many patients ended up in a vicious circle, where poverty and possible co-infections (HIV) led to slow recovery, and where slow recovery contributed to income poverty and further dependency. These barriers manifested themselves at a time when psychological and other costs had accumulated, and enablers like family and community support were decreasing. This study shows that illness-induced poverty over time threatens the sustainability of household finances, as well as the social relations that serve as the basis of the household's continued existence as a social unit.

Our findings suggest that it is important that the health care system is aware of the dynamics of social support mechanisms. In Ethiopia there seems to be a change during treatment from a "generalised" to a more "balanced" type of reciprocity. This movement seems to be consistent with symbolic and practical changes related to completion of the first stage of treatment (the intensive phase), but may also be a product of increasing HIV/TB co-infection rates. In people's experiences, patients with prolonged diseases or intermittent symptoms often die, and social support may therefore now be withdrawn earlier than before.

Validity and transferability

The trustworthiness of the study and validity of our findings is strengthened by the extensive triangulation within the study. We interviewed different groups of patients, health professionals and patients' relatives. The same themes were investigated from both a prospective and a retrospective angle, by means of different methods. Our findings are characterized by similarities within and between different groups of respondents and we believe this strengthens the internal validity of our study.

The sample size is limited and restricted to one geographical area, and instead of proposing that the findings are transferable to other contexts, we suggest using the concept of "extrapolation" [38] to describe the usefulness of our study. Patterns of findings presented in a broad contextual frame enable us to be aware of potential similarities in similar contexts, in particular how variables may interrelate at time-specific points in treatment and how certain identifiable patterns may create barriers in relation to the management of treatment.

TB control managers and others may argue that by not strictly following NTLCP's operational definition of a defaulter the findings will be less applicable. We believe the implications are few since the strict definition is mainly used to separate between defaulters who re-enters treatment being smear positive again, and patients that may recommence treatment to finish the initial regimen. An important implication though may be increasing awareness of patients that may "default" due to poverty related barriers early in treatment (< 4 weeks), but that are not registered as defaulters. The criteria used for defining defaulters may result in relatively low overall rates of default, also pointed to in another study from Ethiopia [23].

Implications for practice

To our knowledge there are few major changes in how the DOT services are organized in Addis Ababa. One change that has been made is the establishment of a formal collaboration between services related to TB and services related to HIV/AIDS [39]. However, a recent study examining the acceptability of HIV testing among TB patients, conclude that the acceptability is low, and that it poses a challenge to the scale-up of TB/HIV collaborative efforts [40]. The findings in the present study may help to predict treatment interruption during the early stages of treatment, based on patients' socioeconomic and environmental conditions. Some of the barriers patients experience during the intensive phase could easily be solved with more flexible approaches, such as more flexible hours for attendance and greater flexibility related to participation in important cultural and family-related events. A primary nurse-patient system, where patients are followed up by the same nurse, would help health personnel to identify each patient's resources and constraints. More individual approaches will make it easier to establish relations based on trust, and will facilitate flexible adjustments by means of follow-up talks throughout treatment.

We believe that TB programs need to address nutrition. As recognized by many patients, without food medical treatment is in vain. Providing one glass of milk or a small meal at the clinic could have a positive influence on both case detection rates and treatment completion. By ensur-

ing access to some nutritious food, patients may gain weight and recover faster, probably the best way to fight stigma and to strengthen social support mechanisms during later stages of treatment. Initiating a dialogue with labour organizations to help prevent TB patients losing their job is another important step.

Still, many patients will experience difficulties related to daily attendance. Further decentralization of TB-related health care, use of mobile clinics, the provision of transport money and permitting some of the poorest or most ill patients to take tablets home for self-treatment may be means to increase adherence. A recent review of randomized controlled trials, comparing DOT with self-administration of therapy, provides no evidence that the routine use of DOT in low- and middle income countries improves cure or treatment completion in people with tuberculosis [5]. Several authors have advocated a shift in perspective, where patients' socioeconomic environments, their well-being's and their dignity are included in future strategies [2,41,42]. Strategies based on self-treatment can be strengthened by support and supervision by an identified relative or neighbour, or through other social structures. Several TB control programmes that leave the choice of DOT supervisor to the patient have been shown to be successful [43-45].

In order to enable patients to get well, one need to make an assessment of what formal and informal sources of support exist, what structures are missing, and how different contributors can fill the gap [2]. In Ethiopia, the involvement of social support structures beyond relatives seems to be important. One useful structure could be the *edir*, a community based body with social responsibility (mainly for arranging funerals) for those living within a defined community (Kebele). The *edir* could become involved through the appointment of persons to be in charge of supporting TB patients who are unable to attend treatment on a daily basis. Social support structures could also be established based on the model of the successful "TB clubs", which are small groups of patients who live near each other, implemented in some rural parts of Ethiopia. These clubs, which collaborate with health workers and key persons in the community, have become an integral part of the tuberculosis program by referring suspected cases, promote treatment adherence and trace patients who interrupt [33,46]. Existing community mechanisms can be strengthened by involving the communities and creating a climate of awareness and shared responsibility for solving major health issues. By involving the communities, more flexible arrangements can be facilitated, the treatment burden can be reduced, and a better balance can be ensured between control measures and enabling measures.

Conclusion

Patients' ability to manage TB treatment is a product of dynamic processes, in which various social and economic costs and other burdens change and interplay over time. Interventions to facilitate adherence to TB treatment need to address both time-specific and local factors.

Competing interests

The author(s) declare that they have no competing interests.

Authors' contributions

MS initiated the research, wrote the research proposal, conducted the research, analyzed the data and wrote this paper. JCF contributed to the conception and design of the study and the analysis and interpretation of the data. He also contributed to the writing of this paper by critically revising it. GB contributed to the conception and design of the study. He also contributed to the writing of this paper by critically revising it. All authors read and approved the final manuscript.

Acknowledgements

We deeply thank Armauer Hansen Research Institute (AHRI) for all the friendliness and all the practical and professional help we received both before and during the study. Our particular thanks must go to our interpreter and research assistant, Minas Abera, for his enthusiasm and for his valuable contributions to the study. We also want to thank all the nurses, health officers and directors at the clinics involved. We are thankful to Jan van den Hombergh, former WHO TB/Leprosy Advisor at the Ministry of Health in Ethiopia, for his cooperation all throughout the project. Finally, we thank the patients and the other participants for their patience, honesty and for sharing their thoughts, struggles and sorrows. This study received financial support from the Norwegian Heart and Lung Association, Norwegian Foundation for Health and Rehabilitation, and Ivar Helles Legat.

References

1. Corbett EL, Marston B, Churchyard GJ, De Cock KM: **Tuberculosis in sub-Saharan Africa: opportunities, challenges, and change in the era of antiretroviral treatment.** *Lancet* 2006, **367**:926-937.
2. Lienhardt C, Ogden JA: **Tuberculosis control in resource-poor countries: have we reached the limits of the universal paradigm?** *Trop Med Int Health* 2004, **9**:833-841.
3. Addington WW: **Patient compliance: the most serious remaining problem in the control of tuberculosis in the United States.** *Chest* 1979, **76**:741-743.
4. Cuneo WD, Snider DE Jr: **Enhancing patient compliance with tuberculosis therapy.** *Clin Chest Med* 1989, **10**:375-380.
5. Volmink J, Garner P: **Directly observed therapy for treating tuberculosis.** *Cochrane Database Syst Rev* 2006:CD003343.
6. Khan MA, Walley JD, Witter SN, Shah SK, Javed S: **Tuberculosis patient adherence to direct observation: results of a social study in Pakistan.** *Health Policy Plan* 2005, **20**:354-365.
7. Menegoni L: **Conceptions of tuberculosis and therapeutic choices in Highland Chiapas, Mexico.** *Med Anthropol Q* 1996, **10**:381-401.
8. O'Boyle SJ, Power JJ, Ibrahim MY, Watson JP: **Factors affecting patient compliance with anti-tuberculosis chemotherapy using the directly observed treatment, short-course strategy (DOTS).** *Int J Tuberc Lung Dis* 2002, **6**:307-312.
9. Dodor EA, Afenyadu GY: **Factors associated with tuberculosis treatment default and completion at the Effia-Nkwanta**

- Regional Hospital in Ghana.** *Trans R Soc Trop Med Hyg* 2005, **99**:827-832.
10. Nair DM, George A, Chacko KT: **Tuberculosis in Bombay: new insights from poor urban patients.** *Health Policy Plan* 1997, **12**:77-85.
 11. Needham DM, Bowman D, Foster SD, Godfrey-Faussett P: **Patient care seeking barriers and tuberculosis programme reform: a qualitative study.** *Health Policy* 2004, **67**:93-106.
 12. Ray TK, Sharma N, Singh MM, Ingle GK: **Economic burden of tuberculosis in patients attending DOT centres in Delhi.** *J Commun Dis* 2005, **37**:93-98.
 13. Jaiswal A, Singh V, Ogden JA, Porter JD, Sharma PP, Sarin R, Arora VK, Jain VC: **Adherence to tuberculosis treatment: lessons from the urban setting of Delhi, India.** *Trop Med Int Health* 2003, **8**:625-633.
 14. Khan A, Walley J, Newell J, Imdad N: **Tuberculosis in Pakistan: socio-cultural constraints and opportunities in treatment.** *Soc Sci Med* 2000, **50**:247-254.
 15. Sanou A, Dembele M, Theobald S, Macq J: **Access and adhering to tuberculosis treatment: barriers faced by patients and communities in Burkina Faso.** *Int J Tuberc Lung Dis* 2004, **8**:1479-1483.
 16. Comolet TM, Rakotomalala R, Rajaonarivo H: **Factors determining compliance with tuberculosis treatment in an urban environment, Tamatave, Madagascar.** *Int J Tuberc Lung Dis* 1998, **2**:891-897.
 17. Edginton ME, Sekatane CS, Goldstein SJ: **Patients' beliefs: do they affect tuberculosis control? A study in a rural district of South Africa.** *Int J Tuberc Lung Dis* 2002, **6**:1075-1082.
 18. Greene JA: **An ethnography of nonadherence: culture, poverty, and tuberculosis in urban Bolivia.** *Cult Med Psychiatry* 2004, **28**:401-425.
 19. Ethiopian Ministry of Health: *Annual Review Addis Ababa*; 2001.
 20. Getahun H, Aragaw D: **Tuberculosis in rural northwest Ethiopia: community perspective.** *Ethiop Med J* 2001, **39**:283-291.
 21. Michael KW, Belachew T, Jira C: **Tuberculosis defaulters from the "dots" regimen in Jimma zone, southwest Ethiopia.** *Ethiop Med J* 2004, **42**:247-253.
 22. Shargie EB, Lindtjorn B: **Determinants of Treatment Adherence Among Smear-Positive Pulmonary Tuberculosis Patients in Southern Ethiopia.** *PLoS Med* 2007, **4**:e37.
 23. Tekle B, Mariam DH, Ali A: **Defaulting from DOTS and its determinants in three districts of Arsi Zone in Ethiopia.** *Int J Tuberc Lung Dis* 2002, **6**:573-579.
 24. Demissie M, Kebede D: **Defaulting from tuberculosis treatment at the Addis Abeba Tuberculosis Centre and factors associated with it.** *Ethiop Med J* 1994, **32**:97-106.
 25. World Health Organization: *Adherence to long term therapies: evidence for action.* Geneva 2003 [http://www.emro.who.int/ncd/Publications/adherence_report.pdf].
 26. World Health Organization: *Global Tuberculosis Database. Country profile on tuberculosis: Ethiopia* [http://www.who.int/globalatlas/predefine_dreports/tb/PDF_Files/eth.pdf].
 27. Ethiopian Ministry of Health: *Tuberculosis and Leprosy Control Program Ethiopia. Introduction and Performance (July 1999-June 2000)* Addis Ababa; 2001.
 28. Becker MH, Maiman LA: **Sociobehavioral determinants of compliance with health and medical care recommendations.** *Med Care* 1975, **13**:10-24.
 29. Flick U: *An introduction to qualitative research* London: Sage Publications; 2002.
 30. Giorgi A: **Sketch of a psychological phenomenological method.** In *Phenomenology and psychological research* Edited by: Giorgi A. Pittsburgh, PA: Duquesne University Press; 1985:8-22.
 31. Malterud K: **Shared understanding of the qualitative research process. Guidelines for the medical researcher.** *Fam Pract* 1993, **10**:201-206.
 32. Christensen-Szalanski JJ, Northcraft GB: **Patient compliance behaviour: the effects of time on patients' values of treatment regimens.** *Soc Sci Med* 1985, **21**:263-273.
 33. Demissie M, Getahun H, Lindtjorn B: **Community tuberculosis care through "TB clubs" in rural North Ethiopia.** *Soc Sci Med* 2003, **56**:2009-2018.
 34. Getahun H: **Medical and social consequences of tuberculosis in rural Ethiopia.** *Ethiop Med J* 1999, **37**:147-153.
 35. Demissie M, Lindtjorn B, Berhane Y: **Patient and health service delay in the diagnosis of pulmonary tuberculosis in Ethiopia.** *BMC Public Health* 2002, **2**:23.
 36. Barnhoorn F, Adriaanse H: **n search of factors responsible for noncompliance among tuberculosis patients in Wardha District, India.** *Soc Sci Med* 1992, **34**:1291-306.
 37. Coleman RL, Wilkinson D, McAdam KP: **Voluntary lay supervisors of directly observed therapy for tuberculosis in Africa.** *Trop Doct* 1998, **28**:78-80.
 38. Alasuutari P: *Researching Culture: Qualitative Method and Cultural Studies* London: Sage; 1995.
 39. The Federal Ministry of Health of Ethiopia: *TB/HIV implementation guideline* Addis Abeba; 2005.
 40. Jerene D, Endale A, Lindtjorn B: **Acceptability of HIV counselling and testing among tuberculosis patients in south Ethiopia.** *BMC Int Health Hum Rights* 2007, **7**:4.
 41. Doyal L: **Moral problems in the use of coercion in dealing with nonadherence in the diagnosis and treatment of tuberculosis.** *Ann N Y Acad Sci* 2001, **953**:208-215.
 42. Porter JD, Ogden JA: **Missed opportunities? Coercion or commitment: policies of prevention.** *Ann N Y Acad Sci* 2001, **953**:224-232.
 43. Adatu F, Odeke R, Mugenyi M, Gargioni G, McCray E, Schneider E, Maher D: **Implementation of the DOTS strategy for tuberculosis control in rural Kiboga District, Uganda, offering patients the option of treatment supervision in the community, 1998-1999.** *Int J Tuberc Lung Dis* 2003, **7**:S63-S71.
 44. Nyirenda TE, Harries AD, Gausi F, van GJ, Maher D, Floyd K, Salaniponi FM: **Decentralisation of tuberculosis services in an urban setting, Lilongwe, Malawi.** *Int J Tuberc Lung Dis* 2003, **7**:S21-S28.
 45. Maher D: **The role of the community in the control of tuberculosis.** *Tuberculosis (Edinb)* 2003, **83**:177-182.
 46. Getahun H, Maher D: **Contribution of "TB clubs" to tuberculosis control in a rural district in Ethiopia.** *Int J Tuberc Lung Dis* 2000, **4**:174-178.

Pre-publication history

The pre-publication history for this paper can be accessed here:

<http://www.biomedcentral.com/1471-2458/8/11/prepub>

Publish with **BioMed Central** and every scientist can read your work free of charge

"BioMed Central will be the most significant development for disseminating the results of biomedical research in our lifetime."

Sir Paul Nurse, Cancer Research UK

Your research papers will be:

- available free of charge to the entire biomedical community
- peer reviewed and published immediately upon acceptance
- cited in PubMed and archived on PubMed Central
- yours — you keep the copyright

Submit your manuscript here:
http://www.biomedcentral.com/info/publishing_adv.asp

